# UNFITTING PARTS

## The Moral, Political and Informal Economies of 'Japanese' Organ Transplants

ALESSIA COSTA

Thesis submitted for the degree of PhD

2015

Department of Anthropology and Sociology
SOAS, University of London

**Declaration for SOAS PhD thesis**

I have read and understood Regulation 17.9 of the Regulations for Students of the SOAS, University of London concerning plagiarism. I undertake that all the material presented for examination is my own work and has not been written for me, in whole or in part, by any other person. I also undertake that any quotation or paraphrase from the published or unpublished work of another person has been duly acknowledged in the work which I present for examination.

Signed: _____ Date: _____

## ABSTRACT

Based on one year of ethnographic fieldwork in Tokyo, this thesis explores the 'economies' of organ transplants in, and from, Japan.

In Japan, the national debate over brain death has resulted in an impasse regarding transplantation medicine that still places the country at the very bottom of international statistics for organ donation. While previous research has investigated in detail the Japanese controversy over brain death, this thesis investigates the so far largely overlooked problem of organ shortage.

Taking up the narratives of transplant recipients who pursued care overseas, and their families, I analyse the phenomenon of travel for transplantation purposes from Japan to North America, casting light on a form of patients' mobility that remains poorly addressed within the growing debate on so-called 'transplant tourism'.

Drawing on extended life narratives and participant observation, I discuss what it means to be a 'transplanted person' (*ishokusha*) in Japan. I discuss how Japanese patients pursue care and ponder delicate clinical decisions, how they navigate their life after the operation, and how they became key policy actors lobbying for reform of the national law on transplants.

Further, I explore how the policy on brain death and transplants is applied in clinical practice, highlighting the question of how to better reconcile possible solutions to the problem of organ shortage, which transplant advocates successfully made the subject of national debate, and the long-enduring controversy over the definition of death.

Compounding the analysis of local and global political economies of care with the personal experience of patients and their families, I introduce the mediators of local economies of organs, and describe the networks of social and moral obligations in the exchange of human body parts.

# TABLE OF CONTENTS

# Acknowledgements

I own my mistakes and owe immensely to all the people with whom I shared this PhD.

My deepest *kansha* goes to the people I worked with in Japan. Their stories changed me profoundly, and I hope that this work does justice to them.

I am especially thankful to my supervisors, Dr. Dolores Martinez and Dr. Christopher Davis, for their guidance and inspiration. I also want to thank the other members of the SOAS Anthropology Department I worked with, in particular Prof. Trevor Marchand, Dr. Edward Simpson, Dr. Caroline Osella, Dr. Fabio Gygi, as well as to the students I had the pleasure to teach. I owe greatly to their passion for a discipline that has changed me in ever-enduring ways.

I am grateful for the generous contributions provided by the Meiji Jingu, the family of Tsuda Kyoko, the SOAS Japan Research Centre, and the British Association for Japanese Studies, which made the completion of my fieldwork possible.

I also want to thank all my fellow anthropologists and the senior academics who contributed to this thesis. In particular, Prof. Glenda Roberts, for accepting me as a visiting fellow at the Graduate School of Asia-Pacific Studies of Waseda University, Dr. Simon Cohn and Dr. Inge Daniels, for examining my thesis and contributing their precious insights. Dr. Aita Karuoko, Dr. Kitanaka Junko,, Dr. Yamazaki Goro, Dr. Yosuke Shimazo, Dr. Ikuko Tomomatsu, Dr. Alessandro Lupo, Dr. Erica Eugeni, Dr. Donatella Cozzi and Dr. Pino Schirripa, for their kind support and invaluable feedbacks.

A special thank goes to my PhD cohort, for making these four years an intellectually and humanly enriching experience. In no particular order, Eddie Bertozzi, Caitlin Robinson, Anna Baral, Maddalena Chiellini, Rob Simpkin, Sahil Warsi, Karin Ahlberg, Carl Rommel, Nadeem Karkabi, Nayantara Premakur,

Maureen Pritchard, Sarah Elsing, Seamus Murphy, Kat Cagat, Jessica Chu, Shirley Martin, Safitri Widagdo, Ela Felinczak, and Anny-Mary Decatur.

Taking my mind off this thesis was of the greatest help to finish it, and so I want to thank all the friends who have been patient enough to hang around during the last four years.

I owe a special debt to each and any of the friends I met in Tokyo. Valentina Di Proietto, Filippo Nuccio, Giovanni Morando, Yosuke Ashida, Natsuko Hatakeyama, Sayaka Kumano, Enrico Conforto, Marco Lazzaro, Kim Lyleen, Matteo Lucci and, last but not least, Simone Tomasi. It was a gift to find them on my way.

I am especially thankful for sharing the experience of this PhD with two formidable anthropologists without whom this thesis would probably not exist. I owe more than I can say to Andrea Enrico Pia, for his unconditional support and friendship. Equally, I owe more than I can repay to Giulia Zoccatelli, who first encouraged me to undertake this project and was with me when I completed it. They have been like family to me.

Finally, this work would certainly not exist without my first family: my sister, Arianna, who shares with me the one thing that more than anything else brought me to this PhD, curiosity, and my parents, Angela and Francesco, who unreservedly supported it. This thesis is dedicated to them.

# Introduction

## “Do You Know about the Wada Transplant?”

Japan is one of the few countries where brain death is not fully recognised as human death and is treated instead as a terminal condition, so that the problem of reconciling the care of the dying person with the need to procure organs remains an open question and profoundly shapes contemporary politics of life and death.

On the 8th of August 1968, at the hospital of the University of Sapporo in the northern island of Japan, Dr. Jirō Wada transplanted the heart of a young man into an eighteen-year-old patient. The operation was the first of its kind in Japan and the thirtieth in history, coming only a few months after Christian Barnard’s famous heart transplant made the headlines worldwide. The Japanese case attracted no less attention. The Japanese media followed it passionately and reported in detail the recovery of the young recipient, Miyazaki-kun, as he uttered his first words after surgery and became able to sit up in bed and eat (Yomiuri 1968*a*, 1968*c*). Dr. Wada, the surgeon trained in America who regarded Japanese medicine as a small “island within the island country” (Yomiuri 1968*b*), became a sort of Japanese counterpart to the medical celebrity Christiaan Barnard. In Japan as elsewhere, organ transplantation caught the imagination of the general public more than any other event in medical research or practice had done before, coming to represent the epitome of the groundbreaking power of modern science and technology. The sensation was huge, but as short as Miyazaki-kun’s recovery.

Less than three months after the operation, the first Japanese heart recipient died. The tragic outcome of what had been depicted as a medical

success brought new attention to the case, and the circumstances of the Wada transplant came under close public scrutiny. The medical experts who conducted the post-mortem suggested that the recipient's condition was not so severe as to require such an invasive intervention, hinting that the real reason for the operation being carried out was in fact Dr. Wada's ambition to join the race to fame. Dreadful suspicions arose over the events that led to the death of the 'donor', which had been determined by Dr. Wada himself. Charges against the surgeon were eventually dropped, but the judgment remains open as to whether the Wada transplant was a gruesome human experiment, intentionally carried out against the ethics of the medical profession, or a decision taken without following established codes of practice. Whichever is the case, the public controversy developed into one of the most heated debates in the history of Japanese bioethics: the so-called "brain death problem" (*nōshi mondai*) (Namihira 1984; Tachibana 1986; Morioka 1989; Ohnuki-Tierney 1994; Feldman 2000; Lock 2002; Long 2005).

Brain death is a neurological condition defined as the irreversible loss of brain function in the entire brain, including the brain stem, resulting in cardio-circulatory arrest. It is on the grounds of the irreversibility and certainty of this prognosis that brain death is equated with human death under the majority of clinical protocols and/or legal systems throughout the world. The redefinition of death as brain death, which historically dates back to the second half of the 1960s, has been an essential step in the development of transplantation medicine, enabling the lawful pronouncement of a person's death even though the heart is still beating, thereby making it possible to procure fresh organs from the dead. In Japan, the public debate that raged in the wake of the Wada transplant brought to the fore the problematic nature of redefining death on neurological criteria in relation to transplantation, and even though the polemic on the Wada transplant eventually petered out the "brain death problem" became one of the longest enduring controversies involving medical ethics in Japan (Namihira 1984; Tachibana 1986; Morioka 1989; Ohnuki-Tierney 1994; Lock 2002; Long 2005; Aita 2011). In the absence of consensus on the problem of whether brain death is human death, transplantation medicine came to an almost complete standstill, and for thirty years after the Wada scandal no

second heart transplant was performed in the country. In 1997, a law was approved which enabled transplantation medicine by authorising lawful organ donation from the brain dead. However, the very strict policy it set up, coupled with the enduring problem of brain death, made organ procurement possible, but resulted in a chronically low donation rate. Thirty years after the Wada case, the law was intended to bring an end to the brain death problem; in fact, the enduring legacy of the controversy over the definition of death is that, to date, Japan has the lowest number of cadaveric organ donations and the longest waiting lists for transplants amongst modern industrialised nations.

> "Thirty years is a long time. In those thirty years, other countries have made big progress, while Japan hasn't. And that's a problem now"
> (Kitanaka-*sensei*).

This thesis looks at this problem, exploring the phenomena of the scarcity of organs, how this came about, how people live with it, and how they seek outside what is in shortage at home. It investigates how the shortage is produced, how it is framed as a problem, and how, in turn, this interweaves with the changing politics of (brain) death.

## The Enduring Legacy of the Brain Death Problem

To begin with a history of transplantation in Japan is no more appropriate (or original) than many other possible openings; nonetheless, it seems compelling to approach the topic by first considering the notorious brain death problem. The ways in which brain death became a matter of controversy in Japan are the subject of more detailed discussion below; first, however, I want to discuss how the brain death problem continues to exert an overwhelming and enduring legacy not only on the practical conditions of organ procurement in Japan, but also on the way that transplantation is talked about in the public discourse and academic literature.

My own engagement with the problem of transplantation stems

primarily from an academic interest in the issue of brain death. I am lucky enough to be able to say that no one in my family or amongst my friends has died in circumstances that required me to consider organ donation; neither did I know, before going to Japan, anyone who was on a waiting list for a transplant. Like many, I had never registered as a donor, despite the conviction that, had I found myself in such a situation, I would have wanted my family to consent to my organs being donated. I had a rather superficial knowledge of transplantation, and remember knowing nothing about the difference between cardiac arrest and brain death before reading about the Japanese case. The way I became interested in this project was because of my familiarity with Japan, and through the anthropological literature on the brain death problem.

In Japan, the controversy surrounding brain death has grown into a "national obsession" (Feldman 2000: 51). Without resorting to hyperbole, I can say that Japanese publications on the brain death problem are innumerable. Legal scholar Bai Kōichi (1980), bioethicists and philosophers Morioka Masahiro (1989), anthropologist Namihira Emiko (1988), sociologists Nudeshima Jirō (1991) and Aita Karuoko (2011; 2012), and journalist Tachibana Takashi (1986) are only the best known authors to have tackled an issue which enjoys ever-lasting popularity across the disciplines. As is often the case in the Japanese publishing world, specialist works have reached a wide readership, well beyond academia, and can commonly be found in bookshops alongside popular literature, which includes titles by patients' families and organisations.

Outside of Japan, the controversy over brain death has become a matter of interest and curiosity, with the international media picking up on the problem (New York Times 1987, 1997), and scholars in the field of bioethics commenting on the Japanese way of handling the new definition of death (Bagheri 2007). Anthropologists based in North America have notably provided insightful analyses into the debate (Ohnuki-Tierny 1994; Lock 2002; Long 2005). Long's work provides an insightful analysis of the wider problem of end-of-life care in Japan and America, tackling a problem of great social relevance and yet scarcely investigated in anthropology (2005).

Her work is very helpful in understanding the cultural worlds in which end-of-life decisions are negotiated, better understood if combined with a closer analysis of how social institutions and structural conditions in health-care provision shape people's choices (cf. Kaufman 2006; Aita 2012). Ohnuki-Tierney and Lock have looked more specifically at brain death, and the different reactions it arouses on opposite sides of the Pacific. Ohnuki-Tierny focuses on cultural differences, reproducing dogmatic and rigid opposition between Japan and the West, explaining the Japanese debate as culturally informed rejection of medical 'rationality' and leaving the analysis short of insight into the wider condition (1994). Lock's argument, on the other hand, is much more nuanced and therefore powerful (2002). Like Feldman (2000), Lock draws on a variety of Japanese sources to combine a cultural critique of brain death with an attentive analysis of the role of political institutions, medical professionals, and the media. Her brilliant argument on the social construction of death in Japan and America is a classic in the ethnographic repertoire on Japan and medical technology. Indeed, it has been so influential that it has become 'fact'. Instead of opening the way to anthropological enquiry into organ transplantation in Japan as a potentially rich and worthy subject of investigation, her compelling analysis of brain death seems to have exhausted the discussion.

In a similar fashion, the dispute about brain death among the Japanese public has, arguably, framed the general perception, professional attitudes, and political discussion on organ donation and transplantation, making the question of defining death the kernel of the problem. Very differently from most other countries, where brain death is only mentioned in passing, if at all, and the dispute on the philosophical coherence, clinical accuracy, and legal implications of the concept has remained an issue for a small group of experts to dissect, in Japan the question of whether brain death is human death continues to be of public interest. The result is that the brain death problem seems to be the necessary point of entry and the paradigmatic framework of any discussion on organ transplantation in general.

The first corollary of this is that while the public debate on organ donation and transplant has been rich in Japan, almost nothing has been

said about the experience of the people who actually participate, and invest their hopes, in this technology, and whose lives are shaped by it. Compared to the ethnographic analyses of the experience of transplant recipients in other countries (Sharp 1995, 1999, 2006; Siminoff and Chillag 1999; Crowley-Matoka 2005; Maynard 2006), a similar discussion with reference to Japan is conspicuous by its absence from anthropological literature. Tomomatsu (2013) and Yamazaki (2007, 2009, 2011a, 2011b) are two rare exceptions. Tomomatsu's work is an in-depth exploration of the experience of Japanese heart transplant recipients that focuses on the patient's negotiation of risks, expectations, and the significance of the operation with respect to local notions of the gift and the body (Tomomatsu 2013). Yamazaki has also tackled the issue of patients' experience, including the topic of medical travel (2007), and has published theoretical contributions to the idea of body economy (2009a, 2011b, 2011b; cf. Waldby and Mitchell 2006) as well as the recent debate on the legal rendition of brain death (2013). In my work, I draw on these two authors, linking the patients' experience, which is Tomomatsu's (2013) focus, to the broader analysis of the economies of organs. In this, I adopt an approach similar to Yamazaki's theorisation of body economies (2009, 2011a, 2011b) to describe how transplant patients' experience, and the problem of defining death, interweave, detailing the ethnographic aspects of the problem, which would otherwise remain unseen.

A review of the two authors who write about Japanese organ recipients leads to a further consideration of how the issue of brain death has functioned as a gatekeeper of the discussion about transplantation in Japan; namely, the fact that, in tandem with the scarcity of data about patients' experience, there is a lack of analysis of the broader networks in which organ transplant are caught up. By this, I refer to the logistical, legal and technical apparatuses informing the practice of organ sharing, as well as the moral dilemmas in which these transactions are tangled. While the problem of scarcity might be particularly acute in Japan, organ transplants are routinely carried out, including, since 1997, all types of solid organ transplants. How then, are cases of donations managed, and how do

potential donations go missing? What are the ethical and legal frameworks that constrain or facilitate organ donation? What social institutions and practices shape the way in which people seek access to care in a regime of scarcity, and with what consequences? Similar questions have been left out of the scope of anthropological investigation, ignoring how the technology of transplant is managed, and not just contested, in Japan. One striking example of this narrowness of focus is that despite the growing interest in transplant mobility and the great relevance of anthropological participation in such a debate (Scheper Hughes 2000, 2001, 2005; Cohen 2001, 2003, 2005), Japan remains effectively off the map of the global movement of organs and patients regardless of its role as the major “organ importing country in the world” (Shimazono 2007).

One final consideration follows closely from this. If a contribution to the anthropological analysis of brain death in Japan is to reflect back on such a concept from a cross-cultural perspective, the focus on cultural differences could very easily be narrowed to reductionist interpretations and representations. Put simply, when the whole debate on transplantation in Japan is reduced to just the brain death problem, the idea is reproduced that the Japanese might have it right, but they still have it differently. Alongside Japan's invisibility on the global map of transplant mobility lies its isolation and self-containment from the debate on brain death. This way of looking at the problem reproduces a gap between Japan and the rest/West, one that can, at best, be filled by sensitive cultural translations (of which the anthropologist is the ultimate gatekeeper), or, at worst, be taken as synonymous with irreconcilable differences that have long rendered sterile any productive analysis of Japan as a field in anthropology (see more below). In this sense, until competing and varied perspectives on the problem of organ donation and transplant in Japan are fully explored, the very contribution of even the most insightful analyses on brain death risks falling prey to the same cultural reductionism they challenge. Almost twenty years after organ transplants from brain dead donors have become a reality in Japan, filling the gaps in the anthropological analysis of this technology is both timely and relevant.

# Organ Transplantation in Japan

The idea from which this project stems, was to look at the other side of the story: the experiences, claims and views of transplant candidates/recipients, their families and the organisations that support them. In a regime of severe and chronic shortage, how do people whose life, and quality of life, depend on the possibility of getting a transplant, seek access to treatment? What are the moral horizons within which these delicate decisions are taken? How do patients and their families negotiate their treatment choice in a society where resources are scare and the question of brain death lingers heavily in the public debate on transplant? How do their illnesses and therapeutic experiences shape the ways in which patients negotiate their relationship with treatment, both in their personal life and with respect to the public controversy over this technology? And what do these experiences tell us about the current situation of transplantation in Japan and its on-going transformations?

One of the first things one learns about Japanese transplant recipients is that many do not stay in Japan. Given the high quality of the national health care system, which translates into the possibility of receiving timely diagnoses and life-support treatment for advanced organ failure, and considering the relative wealth of middle and upper class Japanese citizens, it is perhaps no surprise that one result of the long waiting times at home is the consistent flow of patients to overseas medical facilities. Lesser known is that alongside this organ 'black market', which has been brought to public attention in somewhat sensational ways, there also exist forms of international mobility for transplantation purposes that do not involve trafficking, coercion or the buying and selling of organs. It is in fact on such forms of transplant mobility to North America, Europe and Australia, that many Japanese patients have increasingly come to rely over the years, in order to pursue treatment scarcely available at home.

On the other hand, given the particular history of transplantation in Japan, recipients are crucial subjects in the “promotion of transplantation” (*ishoku wo suishin suru*) at home. Becoming an organ recipient means

entering dense networks of relationships with fellow patients, medical doctors, professionals in the field of transplantation and patients' support organisations. Japanese patients strategically draw on these connections for navigating their therapeutic experiences both before and after the transplant. Patients' stories are traded in the public discourse on the technology of transplantation, validating the efficacy and value of the treatment, and recipients themselves become actively involved in promoting social awareness about organ donation as a way to pay back the 'gift of life' they have received. In a country like Japan where the transplant technology has long been gauged through the lens of the brain death problem, recipients have come to play a key role in making this treatment accessible and desirable to fellow patients, in shaping the public discourse and debate on the technology, and ultimately in informing government policy on donation and transplant. In doing so, they have mobilised and publicly validated representations and expectations about this technology that had long remained shadowed by the contestation of brain death.

The first event I attended in the field was the so-called Ginza Parade, a public demonstration that recipients' groups organise annually to promote social sensibility about organ donation and to call on the government to support transplant through favourable policies and with adequate funding. The 2011 event I attended was the last traditional Ginza Parade, which had run consecutively for the previous fifteen years. The year before, a new public policy had been enforced that, for the first time since the legalisation of organ donation in 1997, intervened in the structural conditions informing the transplantation system in the country with the aim of alleviating the chronic shortage of organs. Passed on the wave of recipients' public mobilisation, the reform of the policy on brain death and transplantation was regarded by transplant advocates as the ultimate achievement in their effort to contribute to the promotion of transplantation in the country.

The reform of the law represented a symbolic moment of change and materialised transformations that had built up for years, but whether, and how, it will have an impact on the situation of organ transplantation in the country depends on a wide range of interrelated factors. In this sense, my fieldwork took

place during a phase of transition in the politics of transplantation, at least one explicitly perceived as such, when important transformations had occurred whose practical effects remained to be seen.

The donation rate in Japan has been constantly, but slowly, on the rise since the legalisation of cadaveric organ donation in 1997, and the reformed policy enforced in 2010 proved effective in producing a further increase in organ donors (see Appendix 1). People in the field, whether patients or professionals, were generally optimistic that, with time, organ donation would become routine in Japan, filling in the gap between the desperate demand for organs and the national shortage of these precious resources. For this to happen, however, much remains to be done, and while the reform of policy represented a visible achievement in the attempt to set up an efficient system for organ procurement in the country, the way things have worked out in practice is a very complex and multi-faceted issue. A closer look at the data on organ donation, for example, reveals that the impact of the revised regulation is not a uniform one. The majority of new donation cases are in fact performed after the patient's cardiac arrest, and not in a condition of brain death, meaning that only kidneys and not other solid organs can be procured. Furthermore, brain death in children continues to remain a sensitive issue, and paediatric organ donation is particularly rare, even compared to the national rate of organ procurement from adult patients. In this sense, the situation following the reform reveals that scarcity is constantly mutating but is rarely ever solved, so that whether the gap between Japan and other countries, and the one between demand and supply, will change, or whether any given solution will work, remain questionable.

The reform of the policy on donation coincided with an increase in government funding to the Japan Organ Transplantation Network, the public agency in charge of organ procurement and allocation for the country. According to professionals in the field, expanding the agency and fostering the creation of a system for organ sharing was the next step once bureaucratic impediments had been removed by pubic policy. Hiring new coordinators and training in-house medical staff to operate as facilitators between the JOTNW and medical doctors is of paramount importance in order to produce favourable conditions for organ procurement on the ground. Fostering cooperation

between the various intensive care specialists arguably remains the sticking point, considering that this sector of the medical world in Japan is traditionally sceptical about organ donation and particularly conservative with respect to the issue of withdrawing life-support from terminal patients.

Concurrently with the promotion of professional cooperation, public awareness is another aspect in which the JOTNW is investing. Publicity and media campaigns seem to be regarded as particularly important in overcoming social sensibility about organ donation and the efficacy of such a contested treatment. Adverts about organ donation are fairly common on the underground, on the streets and in the media, and the JOTNW seems to be launching new events every year, from pop concerts dedicated to organ transplants, to celebratory initiatives like the lighting-up of public buildings in green, the symbolic colour of organ donation. More than emphasising the needs of recipients, these campaigns commemorate the social significance of transplantation and construct positive images of organ donation. In particular, they urge people to consider donation regardless of their decision about end-of-life care, and to use donor cards to express their will. In this way, they reproduce a distinctive view of organ donation, consequent upon the debate over brain death, as a question pertaining to the end-of-life more than to one's legacy after death.

While the public discourse on donation and transplants has largely been framed through the lens of brain death, recipients' personal testimonies and stories have contributed to bringing forth new perspectives on the problem. Many of the people who participated in my research, for example, cooperated with organisations promoting transplantation and were used to giving speeches at public events and seminars, and lectures in schools. Many of them also released interviews on the media, featured in various TV specials, and published their own memoirs about the experience of becoming a recipient or of losing a loved one because of the shortage of organs. By sharing their stories, they have contributed to articulating new, positive images of the social worth of transplantation, as well as identifying problems other than that of brain death.

This is not to say that brain death is no longer a matter of concern, quite the contrary. During my time in Japan I attended a meeting at the Parliament

organised by MPs from left wing parties opposing brain death in collaboration with the Network for the Revision of the Law on Transplants (*zōki ishoku ni kansuru hōritsu*), confusedly named after the reform of the same law that transplant activists too lobbied to revise, but in fact advocating an amendment in the opposite direction. The association was formed by opponents of brain death, such as groups supporting the rights of disabled people, terminal patients, and car accident victims. One of the speakers invited to that meeting was the mother of a teenage girl who committed suicide after being bullied at school. The woman had since campaigned against *ijime* (school bullying) calling for a redefinition of cases like the death of her daughter from suicide to homicide. In her view, suicide is only the trigger (*kikkake*) for these deaths, the real cause (*genri*) being peer violence at school. The same logic, she argued, applied to the new policy for organ donation that currently allows organ procurement with family's consent only, even though the patient is not registered as a donor. Under such conditions brain death becomes just a trigger to facilitate organ procurement instead of representing the patient's will.

The episode well illustrates that not only hasn't the firm objection to brain death disappeared, but also that the issue is so pervasive and has become so deeply embedded in the public debate about the end of life and patients' rights, that it functions as an outlet for articulating wider social concerns. The media frenzy over brain death seemed be to rekindled on the occasion of the political debate on the reform of the policy on organ donation in 2009, but attention to the problem is always high, with every case of donation from brain dead patients reported on the national news (less so when organs are procured from non-heart-beating donors). Halfway through my fieldwork, the first case of paediatric donation happened, involving a brain dead boy under the age of six. Journalists crowded outside the hospital where the baby boy died and for several days reported the unfolding of the event: from the pronunciation of death of the patient, to the procurement and dispatch of the organs, the selection of recipients, and the outcome of the transplants. As was routine, the JOTNW held a press conference to give general information about the case and avoid further intrusion form the media, but, exceptionally, a statement by the

patient's family was released the generic contents of which were widely reported on the news.

Brain death, it seems, never ceases to be a matter of public interest, nor stops being an issue of particular relevance in the field of professional bioethics. The topic figures regularly in the contents of specialist journals and conferences, usually discussed in association with organ transplantation but also, quite differently from other countries, with relevance to end-of-life care. In clinical practice, brain death presents considerably fewer dilemmas than conditions with uncertain prognoses, such as persistent vegetative states, and despite the relative simplicity of the therapeutic options it presents, brain death is practically synonymous with the broader debate on treatment withdrawal/withholding (Aita 2011). In fact, as the problem of death with dignity seems to become an increasingly relevant one in medical circles and the public arena, the case of brain death represents a precedent by which to gauge other issues, while the dilemma of how to care for brain dead patients (including potential organ donors) appears all the more relevant.

As this brief description of the situation in the field suggests, to look at the other side of the story does not mean ignoring brain death, but does acknowledge the existence of voices, experiences and claims that the intellectual conundrum of defining death doesn't account for. It means, in fact, to tell a whole different story, one that explores how the problem of defining death as a techno-biological process mutually shapes and shines a light on the medically informed enterprise of 'saving lives'. Before looking at what this means in practice, however, a clarification is needed in order to limit the field of this study, starting from the question of whether organ transplants can ever be 'Japanese'.

## The Anthropology of Japan

Organ transplantation is an example of what Ong and Collier (2005) famously called "global assemblages": trans-national forms characterised by, and dependent upon, their distinctive capacity for moving across different cultural and social settings, decontextualising and reassimilating to new environments and local conditions. Global assemblages appear to be universal phenomena, in the sense that their existence doesn't depend, and rather glosses over, local cultural and social behaviours shared by a specific group (*ibid.*). They are, in the words of Ong and Collier, "limited or delimited by specific technical infrastructures, administrative apparatuses, or value regimes, not by the vagaries of a social or cultural field" (*ibid.*: 11).

In this sense, it seems untenable to speak of 'Japanese' organ transplants. Transplantation is a movable technology and apparatus of knowledge. Although it is often depicted as a technology 'imported' from the West, it is no more Western than Japanese. Certainly, it stemmed from culturally specific conceptualisations of the body and disease, and from historically contingent developments in Western biomedicine, but it is equally informed by biopolitics, economic logics, and social institutions that can hardly be said to have no place in Japanese society (Chapter 1). Furthermore, the transplants I discuss here don't always take place, geographically *in* Japan, they take shape across national and jurisdictional boundaries, in ways that are shaped by transportable technologies and apparatuses of knowledge, and by the global junctions between local infrastructures of health-care provision, national policies, social institutions, grass-roots organisations, and local networks of moral obligations. The meanings and practices underscoring the workings of transplantation are always negotiated on the ground in ways that intersect, collide and conjure the goals and values built into the technology. In this sense, they are indicative and revealing of how transplantation works in the specific context of Japan, not of a larger 'Japanese' society into which a foreign technology is introduced.

Taking these forms of problems, which I referred to through the concept of global assemblages, as a domain of anthropological investigation, raises the

question of how to avoid two opposite methodological biases. The first is assuming that by virtue of their transportability and applicability in various local settings, global assemblages respond to a universal logic that is independent of social conditions, human labour, creation and negotiation, and is therefore a self-explanatory description of 'natural facts'. The implication of this line of reasoning, the second bias, is to reify the social domain as that which lies outside, or even in opposition to, medical science and technology. The two approaches are like two sides of the same coin (Latour 1993). For clarity of analysis I am going to discuss them separately, staring with the second, which in this case means asking what is 'Japanese'.

The question is a vexed one in this anthropological field, and must be considered within the broader intellectual history of the relationships of modern Japan with the West, especially America. For a long time, Japan remained effectively outside the scope of interest of anthropology, and for even longer it remained a field of scarce relevance within the discipline, or in the social sciences more generally, despite occupying a prominent space in public discourse. Popular representations and images of practically every aspects of Japanese social and cultural life abound, testifying to a Western infatuation with the country, that seems to have been going on, albeit in changing forms, at least since the late nineteenth century.

In 1868, Japan 'opened' to the West, initiating a process of rapid political, economic, and social transformations aimed at the creation of a modern nation state attended by changed and closer relationships with European and North American countries (Hall 1970). As Martinez argues, changing social institutions was, overall, the simplest task in the process of rapid and contested transformation that accompanied the formation of the Japanese nation-state throughout the Meiji (1868-1912), Taisho (1912-1926) and much of the early Showa (1926-1989) eras. More complex was the creation of a shared Japanese identity in place of the smaller regional political units that made up the feudal country (2007). Culture emerged as the key domain underscoring the creation of modern Japan, which has always been defined by its cultural politics as much as by its geographical isolation (Gluck 1985). The idea that national culture plays a crucial role in the making of places, is anthropological common

sense, and is something that Japan shares with all nations (Gupta and Ferguson 1982). This, however, does not negate the process of the invention of Japanese culture that happened in specific ways, at a historical juncture when the country was asserting its role against Western colonial powers, while also undertaking a process of modernisation to which science and technology were deemed crucial (Low 2005). Japanese culture, thus, came to be defined in opposition to the West/rest, and to the technology that came from there.

The idea of the Japanese seeking Western technology while still retaining the uncontaminated cultural tradition refined in centuries of isolation, didn't only work to promote modernisation at home, it also caught the attention of a Western audience, intrigued by an aesthetic fascination with the far away country and eager for some "glimpses of the unfamiliar Japan" (Hearn 1901). Coupled with the country's place outside the Western colonial project, early portraits of the Japanese as naïve, childish and bizarre creatures contributed to keep Japan off the mainstream anthropological map, so that, as Ryang ironically puts it, it is no coincidence that Japan "is the only real country that Gulliver, not the anthropologist, travelled to" (2004: 7). In fact, trained anthropologist John Embree did travel to Japan in the 1930s, where he conducted fieldwork in the Suye Mura (Suye village) that gives its name to his monograph (1939). This, however, remained largely overshadowed by a very different approach.

Japan forcibly entered anthropology with WWII, when the cultural idiosyncrasies that had made it intriguing suddenly became synonymous with inhumanity and the threat of the imperial army. Ethnographic knowledge became a weapon to be deployed in service of the American war effort (Price 2008). The notorious result of this anthropological study, the celebrated and contested *The Chrysanthemum and the Sword* (Benedict 1946), would become the progenitor of all anthropology of Japan, in that it created a largely successful representation of who 'the Japanese' are. As Robertson illustrates, the influence of Benedict's monograph, in contrast to Embree's ethnography, speaks volumes in its capacity to offer an "easy and monolithic knowability of Japan" and its people (Robertson 1998: 303). Consistent with its political agenda and its methodological focus on patterns of culture, the

*Chrysanthemum* provided a comprehensive and timeless picture of Japan through which foreigners could claim knowledge of its people, while also mirroring the U.S.A. in the process of describing the exotic other (cf. Geertz 1974). In this sense, through Benedict's book, Japan became quite literally “a thing”, and it was this thing that anthropologists came to study in the following decades and that the Japanese themselves fully embraced and made their own.

Indeed, the Japanese themselves have largely contributed to the circulation of essentialising representations of their own culture and society. While Japanese anthropology, whose tradition dates back to the latter half of the nineteenth century, initially concerned itself mostly with the study of colonial subjects (Yamashita 2004), the gap of countering Western representation of Japan has been filled by the native ‘theory on Japaneseness’ (*Nihonjiron*), a genre preoccupying itself with understanding what makes Japan unique. The rise in popularity of *Nihonjiron* can be seen as a reaction to the success of *The Chrysanthemum and the Sword*, which put Japan, the former coloniser, in the new position of the intellectually colonised (Mathews 2004). In this sense, *Nihonjiron* brought Japan back to the Japanese by strongly asserting the idea of a culture so unique and different to anything else that only the Japanese can really understand it (*ibid.*). Through this intellectual move, the genre reifies the identification of the nation with its (supposedly ethnically homogeneous) people, on the grounds of a shared culture (Befu 2001).

Assumptions of homogeneity have functioned as powerful gatekeepers of the ways in which Japan is apprehended and represented, continuing to inform research in anthropology and social sciences generally, that multiplied after WWII. The post-war period, up to the present day, has seen rapid transformation in the relationship between Japan and the West. The former enemy became a precious political ally of the ‘free world’ and a major trading partner. Japan’s rapid growth into one of the world’s leading economies aroused the puzzled interest of the West in the ‘Japanese miracle’ (Vogel 1979). When recession hit, Japan kept its cool. The rebranding of the country as ‘Cool Japan’, with the government investing in, and the West falling in love with, local fashions, movies, games, the music industry, *manga* and *anime*,

historical heritage and culinary traditions, has ensured the country a firm place in the international arena, continuing to attracting foreign investment, tourists, and scholars alike (Condry 2011).

The decades after the war brought profound internal transformations, but as Sugimoto (2003) describes, social analyses have remained especially insensitive to variations within Japan. As they transformed concordantly with the changing political and economic relationships of with the West, studies of Japan oscillated between the opposite poles of either conflating the Japanese experience with Western models of analysis, or reproducing the idea of a "uniquely unique" Japan irreconcilably different to the rest of the world (*ibid.*). While the first approach remains insensible to local concepts and social conditions, the second reiterates the image of a society whose members uniformly share behaviours and values that are taken to be distinctively 'Japanese'. Both are deaf to the variety of human experience that is the primary interest and ultimate goal of anthropological investigation. In this way, despite the blooming of the anthropology of Japan after the war, this paradigmatic framework of analysis contributed to the marginality of the field within the larger disciplinary debate. As Roberston argues, for a long time Japan, as an anthropological field, was deemed as either too similar to Western complex societies, or too different to anywhere else; too much like 'us' to be of theoretical interest to a discipline that trades in the unfamiliar, or too 'other' to be of any relevance to the wider debate (Robertson 2005; cf. Gupta and Ferguson 1997).

Classical anthropological descriptions of Japan greatly contributed to this paradigmatic framework of analysis through the dogma of Japanese homogeneity. In this sense, Nakane's influence was second only to Benedict's: her totalising portrayl of Japanese society as hierarchically structured, group-oriented and inherently harmonious, set the terms of engagement with Japan in anthropology and beyond, by laying down very clear parameters that define 'the Japanese' (1970). One of the most influential ways in which Nakane's work framed the understanding of Japanese society was by pinning down its distinctive characteristics to dynamics of social interactions that define the relationship between the individual and the group to which one belongs (Kelly

1991). This became a privileged domain of investigation, explored from a variety of perspectives: normative 'patterns of behaviour' (Lebra 1976), processes socialisation (Hendry 1986), local cosmologies (Smith 1974), work (Clark 1979), constructs of self and personhood (Kondo 1990), and the emic concept of relatedness, most famously the idea of *amae* put forth by the psychologist Doi (1973). These works remain important in their regards, for they offer in-depth descriptions of significant aspects of social life in Japan, and provide important insights into the dynamics of interaction, belonging and rationality. However, they often lay down very rigid frameworks of social action and rely on too neat oppositions, such as in describing relations of indebtedness and the distinction between *uchi* and *soto* (see, for example, Hendry 1987). Further, these analytical categories are seldom put to the test looking at less conventional social fields.

Organ transplantation challenges notions of relatedness, reciprocity and exchange, as is often pointed out in the English literature on donation (see below). The ethnographic description of how these transactions are negotiated presents a relevant case study to investigate ideas of indebtedness and relatedness, which have been widely discussed with regards to Japan, and with regards to gift practices (Rupp 2003; Befu 1968), by taking a look at less usual contexts (see Chapters 4 and 5 in particular). This, in turn, offers precious insights that complicate the similarly rigid concepts of gifts and commodities that are often employed in Western literature.

Recent ethnographic trends have articulated a powerful critique of the tired image of Japanese society as homogeneous, static and self-contained. A burgeoning body of literature has highlighted variances and differences, by shedding a light on traditionally ignored social groups, such as women and gender (Martinez 2014), the working class (Roberts 1994), youth and urban subcultures (Kinsella 2014), disabled people (Nakamura 2006), and issues such as gender (Martinez 2014) and sexuality (Nakamura 2014). The theme of globalisation, with the increasing mobility of Japanese overseas and the growing number of immigrants at home, has also received particular attention as fertile ground to challenge notions of Japanese uniqueness based on ethnic homogeneity (Goodman 2002a; Suzuki 2010). Anthropologists have highlighted

changes in key institutions traditionally described as the foundation of Japanese society, accounting for the crumbling of the lifelong employment system and Japanese masculinity (Cook 2009), new religions (Reader 2000) and transforming practices of death from ancestor worship to the commercialisation of funerals (Suzuki 2000, 2013). Official politics and civil society have also emerged as a terrain where special attention is paid to the dynamics of social change and civic participation, thus shaking the assumptions that Japanese society is governed by hierarchical interactions, unquestioned loyalty to superiors and mutual consensus (Fisker-Nielsen 2012).

Despite evident thematic differences, this ethnography is situated in many respects at the intersection of various concepts that these studies highlight. Firstly, it considers Japan on the global scene, looking at nationality not through the lens of ethnicity but from the perspective of medical citizenship (cf. Nguyen 2005), seeing the nation state from a somehow different perspective: that of the trans-national politics of health care. Moreover, it looks at two themes, patients' groups and health related activism, that remain poorly investigated in Japan, despite the relevance of the few existing studies (George 2001; Hirano 2008; Nakamura 2006) and the growing theoretical interest in Western literature (Novas 2006; Rabinow 2005; Rose 2007).

Illness experiences, medical practices and the body entered the scope of investigation of ethnographers of Japan quite early, considering the fairly short history of anthropology in this field. One of the reasons is arguably because the Japanese medical pluralism, combining Chinese medicine and biomedicine, offered fertile terrain for the study of local notions of illness and concepts of the body (Ohnuki-Thierney et al. 1994; Norbeck and Lock 1987). In this regard, historical analyses of the introduction of biomedicine in Japan have offered theoretically insightful perspectives on the relationship between modernity and medical science and technologies, as well as the body's symbolic role in the political project of building contemporary Japan (Yoshikuni 2000; Robertson 2002; Frühstück 2003). Anthropologists of Japan have paid great attention to practices and dimensions of embodiment in the most disparate venues: from traditional religious practices of self-mummification (Raveri 1992), to gender (Spielvogel 2003), beauty (Miller 2006), everyday habits and self-presentation

(Kondo 1990). Surprisingly (or maybe not, see below), considerably less attention has been given to the body as an object of biomedical intervention. It is no coincidence that menopause (Lock 1993), aging (Traphagan 2000), disability (Nakamura 2006), *hikikomori*, or syndrome from social withdrawal (Horiguchi 2011), psychotherapy (Reynolds 1980) and depression (Kitanaka 2012), have attracted the interest of anthropologists, as they are conditions and practices where the influences of the "vagaries of the (Japanese) social or cultural field" appear manifestly. Similarly, pregnancy (Ivry 2010) and reproductive technologies (Kato and Sleeboom-Faulkner 2011) have received particular attention, reflecting the attentiveness to local conceptions of motherhood and gender. Norgren brilliantly discusses contraception and abortion, questioning how to account for the ways in which they are dealt with so differently than in the West (2001). Brain death has, notably, raised similar dilemmas (Lock 2002).

It seems that biomedical science and technology appear to be worth studying only insofar as they are entrenched within socially contingent issues (gender, social stigma, notions of body capability, etc.), or when they are assumed or known to collide with local discourses and practices. I acknowledge that I am overlooking the complexities of many of these works, which indeed provide brilliant critiques of the biomedical model on the ground of sophisticated ethnographic analyses of medicine's workings. Precisely because of the influential and inspirational insights they offer, however, the paucity of studies on medical technologies in Japan is even more sticking. First, it is a major disservice to the anthropology of the field, given that the country is a world-renowned research hub, and that biomedicine is arguably the dominant framework within which people manage death and navigate crucial episodes of illness. Equally importantly, it is a missed chance to understand the workings of medical practices thorough the study of clinical medicine and the social practices that bring technology to life. From this perspective, this ethnography adds to the studies mentioned of medical practice and technology in Japan, as well as to the ethnographic repertoire on organ transplantation in various societies (Hogle 1999; Sharp 2006; Hamdy 2012), in an attempt to offer novel

insights that go beyond the tired opposition between the ‘Japanese’ moral world and Western bioethics (Hoshino 1997).

## The Anthropology of Biomedicine and Biotechnologies

Perhaps it's no surprise that when anthropologists first took up investigating medicine as a field of study in its own right, they focused initially on ethno-medicines, psychology and psychiatry, or on ethnic minorities’ use and understanding of biomedicine (Young 1982). While relevant in their own regards, these approaches either depict medicine as a mere mirror of external social structures and relationships, such as kinship or religion, or focus on psychological and psychiatric states as non-organic or at best psycho-somatic disorders, or confine themselves to people’s experience of illness as marginal, non-compliant and ultimately different from biological knowledge. By doing so, they effectively bracket off biology from the realm of anthropological enquiry, so that, as Young (1982) famously argued, the body remains a “black box” that tells anthropologists nothing and about which anthropologists have nothing to say, with the result that the epistemological scrutiny to which other medicines have been subject was suspended in the case of biomedicine.

Leaving the body un-problematised had enormous methodological consequences, in that anthropologists relied uncritically on the biomedical model of knowledge and adopted its epistemological premises and assumptions as their own (Scheper-Hughes and Lock 1987). Biology remained both a mode of knowledge and the very object of that knowledge, cast out from the realm of human labour and therefore of anthropological investigation; by its very condition it was taken as a given (Franklin 1997). Conflated with nature, biology was regarded as opposed to the social domain, and as the first was conceived of as a matter of fact, so the second was relativised and rendered synonymous with “otherness”; other from nature and consequently other from “our culture” and thus based on science (Latour 1993, 2007). Ironically, by reproducing the distinction between nature and culture, anthropology reified the foundation of an epistemological divide that trivialised it as the “marginal discipline of the

margins" (Latour 1993: 101). Self-limited to descriptions of what is different to "true" scientific knowledge, the anthropology of medicine could at best be co-opted as the handmaiden of clinical compliance.

The growing anthropological interest in the body contributed to a methodologically productive crisis of this model (Csordas 1990; Martin 1992), as recent research on biotechnology has become one of the most fertile sites of anthropological investigation. Contemporary biotechnologies explicitly exhibit the capacity of breaching boundaries once taken as given. What more, they do so in often sensational and controversial ways, to the point that the argument about the unprecedented impact on nature of human interventions has become almost a rhetorical device to discuss these technologies in the public discourse. While they prompt the reconfiguration of the very distinctions they threaten, from an anthropological perspective biotechnologies have contributed to revealing how so-called "natural facts" are actually domains of human creation, choice, aesthetics, power, and moral dilemmas - in short, socially fabricated fields.

Interventions at the beginning and end of life make it particularly clear how biotechnologies are techniques of fabrication of what it means to be human (Kaufman and Morgan 2005). Reproductive technologies and prenatal testing, for example, have brought into being new forms of life that previously did not exist on their own, such as the embryo and the foetus (Martin 1984, Strathern 1998). If these technologies have brought conception into the domain of human intervention and inverted the epistemological relationship between nature and culture (Strathern 1992, Franklin 1997), research on stem cells and genetics has opened up the possibility of shaping life itself at its most infinitesimal level (Rose 2007).

By reconfiguring the building blocks of life itself these techniques allow us to disentangle life from organisms and persons, making them immortal (Skloot 2011) and turning them into "things" of dubious legal, moral and economic value, indeed of uncertain ontological status (Pottage 1998). In this sense, stem-cell research and genetics resemble organ transfer, for they reveal how attending to the disassembling of the body is also the process of redefining the relationship between the body (parts) and the person (cf. Strathern 2004) by

preserving or terminating life. As the controversies surrounding treatment withdrawal, death with dignity and end-of-life care make painfully evident, these are processes of defining the very parameters of life itself. In a historical moment when political rights and ethical choices seem increasingly inscribed in and negotiated through one's biological existence (Fassin 2005; Rose 2007), the capacity of life-support and resuscitative technologies to prolong organic life has prompted the most controversial reflections on what it means to be human (Agamben 1998).

More recently, science and medical technologies have attracted renewed scholarly interest in anthropology and related discipline as social scientists have increasingly turned their attention to the study of Science, Technology and Society (STS). Their contributions have illuminated the material and social processes of the construction of scientific knowledge (Latour 1988), redefining material technologies from inert objects that are actep upon into actors that help creating the social worlds they ihabit (Latour 2005) and the very ontologies of the human body (Mol 2003).

The ethnography below describes problems that are enabled, constrained and at times even forced into existence by the technology of organ transplants, and for metholdogical reasons (see more below) takes humans as its privileged subjects. I ask the question of how the global technology of organ transplant was reassembled in Japan, focusing on the shifting understandings of life and death that shape the negotiation between the medically driven quest for organs and the enduring problem surrounding the process of dying. In doing so, I adopt the analytical framework of economies to describe the circulations of material and non material things through which people manage the procurement and allocation of organs as therapeutic resources. Followig is a more detailed discussion of how this approach is situated within the anthropological literature on the problem of organ donation and transplants and how it contributes to it.

# The Moral, Political and Informal Economies of Organ Transplants

*Theoretical directions in the anthropology of organ transplants*

Organ transplantation has been one of the first fields of social investigation into high-end medical technologies with the pioneering work of American sociologists Renèe Fox and Judith Swezey, among the first social scientists to undertake extensive fieldwork in clinical settings. Between the late 1960s and 1970s, Fox and Swazey worked with transplant surgeons, dialysis patients, organ recipients and their families, producing a pioneering account of organ transplants (1978). The then experimental technology offered the perfect case study for investigating the ethical dilemmas raised by the new branch of techno-scientific medicine. Organ transplant was a widely publicised, experimental procedure that involved high costs, severe risks and uncertain benefits. It mobilised previously unimaginable financial and technological resources, bidding on the lives of patients who had nothing to loose.

The ethics of clinical decisions emerged clearly as a main area of interest for social scientists. At a time when organ transplants were carried out in only a few medical centres and no ethical or regulatory framework existed, the allocation of limited resources (including both organs and funds to develop highly expensive transplant programs) represented a problematic question to settle if the new technology were ever to be implemented. Equally, the selection of donors and recipients and the evaluation of risks and benefits for patients had to be gauged in the absence of data on survival rate and rejection problems. As Fox and Swazey (1978) described, such sensitive decisions were negotiated case by case and within highly hierarchical and patronising doctor-patient relationships. Against such a background, Fox and Swazey's famously described the ethos of transplant medicine in terms of 'the courage to fail' (1978), highlighting that development of the new technology appeared to be driven a moral economy that prised faith in progress, professional ambition and risk-taking, even in the face of poor outcomes for patients.

Along with providing key insights on how clinical decisions were negotiated in practice, Fox and Swazey also focused on the symbolic representation of organ transfer and the relationships they informed. Drawing on Mauss's classical theorisation of the gift (1970), the two sociologists described how the obligations to give, receive and return the 'gift of life' were important factors informing the decisions that living related donors and recipients were confronted with (1978). In partciualr, their analysis highlights that this web of moral obligations placed a particular burden on recipients, producing a feeling of indebtedness that could never be fully paid back (*ibidem*; cf. Shimazono 2008).

Fox and Swazey's research was one of the first attempts to analyse the consequences of biotechnologies' power to disassemble and mobilise human body parts, and the rich array of symbolical imageries and networks of exchange that took shape around it. '*The Courage to Fail*' thus dentified lines of enquiry that would prove incredibly fruitful in the anthropological literature on organ transplantation, and would evolve with the development of transplantation technology into a routine, globally available clinical procedure[7].

With the systematization of large-scale networks for organ sharing, the ethical dilemmas at the centre of Fox and Swazey's ethnography in the hospital ward took on a new, broader dimension. Questions on organ procurement and allocation that were previously negotiated between doctors and patients' families became the matter of concern for national parliaments, ethical committee and the general public, and anthropologists and social scientists increasingly shifted their focus of attention from the clinical encounter to the public debate. Some of the most insightful ethnographies on organ transplants thus look at how these decisions concerning collective life have been taken up and discussed in cross-cultural contexts.

Along with the already discussed case of Japan, Ikels has documented the case of kidney transplantation in China, where local conceptions about the functions of this particular organ, coupled with the resistance toards brain death

[7] Fox and Swazey themselves returned on the topic almost twenty years later (1992), only to abandon it in dismay with the latest developments in the field, particularly the mve towards financial incentives towards donation and the excessive and increasingly indiscriminate use of the technology.

and cadaveric organ procurement had created a particularly acute organ shortage (2012).

Hogle (1999) has provided a rich account of the controversies surrounding organ procurement in Germany at the time when the national parliament was debating on the law on organ donation. Drawing on first-hand ethnography and historical analysis, she illustrates how organ transplantation encountered a difficult public acceptance in Germany and raised questions at the core of modern biopolitics (*ibidem*). Hogle argues that using a person's body to someone else's benefit and contemplating the idea of redefining death to enable large-scale organ harvesting revived the national traumas of Nazi eugenics and East Germany totalitarianism, and that the development of transplants in the country rendered necessary a profound renegotiation of the relationships between citizenship and biopolitics (see more below).

More recently, Hamdy (2012) has documented ethnographically the consequences of the debate on brain death and organ donation in Egypt, a country that has been at the forefront in the race to transplants, and yet has witnessed harsh resistance to the passing of a national law on cadaveric organ procurement. Hamdy maps the evolving of the debate on transplantation over the last three decades, in the midts of the religious opposition to brain death, the deepening of social inequalities and growing civil unrest (*ibidem*). Against this background, she discusses how ambitious and internationally connected medical professionals and patients in need of an organ negotiate decisions over the use of a technology that is not just morally problematic, but also deeply imbricated with social injustice, as the poor are forced to sell kidneys for a living and only the privileged can access care. Recasting the focus from the cultural analysis on the contestation to brain death, Hamdy argues that the debate in Egypt has never been about religion and local traditions vis-à-vis "Western technologies", and points out instead how Egypt offers a case to rethink of bioethics as problem of politics rather than philosophical principles (*ibidem*).

While the redefinition of brain death and its practical implications for organ procurement has thus emerged as a key area of concern in various contexts, anthropologists have been mostly silent on how the matter has been dealt with in North America. Filed as a settled question in the 1970s, the question of brain

death re-emerged as a controversial topic in the American bioethical debate since the late 1980s-early 1990s (see Chapter 1). However, with the exception of Lock (1999), anthropologists have shown scarce interest in the problem, partly reflecting how the issue never raised to wider public attention in the media and public debate in North America. Leaving it to sociologists (Fox 1993), philosphers (Gervais 1986), and medical professionals (Shewmon 1998a, 1998b) to analyse the cultural assumptions underscoring brain death and its place in North America legal system and clinical practice, anthropologists turned instead to themes more akin to the traditional concerns and methods of the discipline.

Anthropologists working on organ transplants in North American have thus mostly focussed on the experience of patients, the symbolic meanings and public representation of organ donation. Among of the most prolific and influential scholars in the field, Sharp has famously contributed one of the richest ethnographic explorations of organ recipients' experience in North America and on patients' subjectivity more in general (2006). Her work has the undoubted merit of illuminating the complexity of the lived experience of treatment, often overshadowed by rhetorical discourses on organ donation, revealing its many problematic implications for individual health, subjectivity and embodiment, as well as social acceptance, stigma and symbolic representations (*ibidem*).

Following on Sharp, the experience of transplant recipients has become an important area of investigation in the anthropological literature on organ transplants. Gordon, for example, have analysed patients' subjective experience of treatment choice (2001), while also drawing attention to the sociocultural factors that influence the selection of candidates at a pre-operative stage (2000). Also writing about the American context, Maynard has drawn attention to the ways in which elective and high-risk double-lung transplant is experienced within a sociocultural context that denies death and disability in favour of the effort of saving life at any costs (2006). Describing very different problems, Crowley-Matoka has illustrated the struggles of Mexican recipients faced with post-oprative complications and prohibitively expensive medication (2005). Looking at the case of Japan, Tomomatsu (2011) has focused on

patients' experience of stigma and subjectivity, while Yamazaki (2011*b*) has described how Japanese organ recipiets conceive the relationship with the organ and the donor through the metaphor of the gift.

Along with patients' experience, anthropologists have also paid a special attention to the web of symbolic meanings and metaphorical imageries that surround organ transplants. As mentioned above, Fox and Swazey already discussed the significance of the gift metaphor, and later studies have further investigated how this shape recipients' subjectivity. At the same time, with the development of transplant medicine on a large scale, anthropologists have also analysed how the trope of the gift informs the political economy of donation and the public perception of the technology (see more below).

A field of enquiry where these problems have emerged as particularly relevant is the problem of organ traffic. With the development of organ transplants worldwide, the buying and selling of body spare parts across legal and national boundaries has become as a pressing issues on anthropologists' research agenda (Scheper-Hughes 2000, 2001, 2005; Cohen 2001, 2003, 2005). Besides casting light on the previously overseen phenomenon of transplant tourism, the anthropological investigation into the black markets of organs has greatly enriched the disciplinary debate on transplants and biotechnologies more in general. The ethnographies of organ traffic articulate an analysis in which the body is no longer a black box around which social and cultural representations are constructed, but is treated as the living embodiment of power relations and economic structures. Ethnographies of organ traffic thus integrate key anthropological insights on structural violence and the effect of global inequalities in the analysis of biotechnologies that so far predominantly looked at nationally bounded realities (cf. Marshall 1992).

Furthermore, the anthropological denounce of organ traffic has contributed to generate significant public interest on the problem, bringing it at the centre of the bioethical debate worldwide. As a perhaps unexpected consequence of the public and scholarly interest on the problem, the debate on the ethics of organ buying and selling seems to have extended from the black market to the domain of legal donation as well. Arguments in favour of regulated markets in human organs that never previously entered the bioethical debate are

nowadays normally discussed in the general media and in academic scholarship (Radcliffe-Richards 1998). Soolars, particularly economitss, have argued that the legalisation of an organ market, or at least of forms of financial incentives to organ donation, would reduce the risks of exploitation and provide an effective way to target the problem of shortage (Stacey 2005;). Public acceptance of the argument seems yet far to reach, and in general discourse free donation still seems to be invested with cherished values of human dignity and fairness. What is sure is that the meanings and implications of construing organ transfer in terms of gift giving are at the core of the debate on organ transplants.

*The gift*

The trope of the gift is a constant theme running through the literature on organ transplants and has often functioned as a paradigmatic framework of analysis in anthropology and closely related disciplines. This might not come as surprise given the special place that the gift has occupied in anthropological and social science literature (see Osteen 2002). As seen with Fox and Swazey's analysis, the legacy of Mauss's landmark theorisation is evident since the very earliest investigation of organ transplant as a social field. Later works have largely drawn on Mauss's argument of the gift as a total social fact, and its corollary implication that our understanding of the gift as a selfless, altruistic act is contextual to the centrality of the commodity in capitalist societies (Parry 1986), to unravel the symbolic meanings and social relationships embedded in organ donation.

Strathern (2004), for example, points out that the practice of construing body parts for medical use as free gifts is deeply rooted in the Western distinction between persons and things. She argues that the legal prohibition of buying and selling persons is grounded in our way of construing things as commodities, whose value is exchangeable for money because they are interchangeable with one another (*ibidem*). A regime of free donation thus allows using body parts as things, while avoid the commodification of the whole body/person and transgressing ideals of human dignity (*ibidem*). In fact, in her ethnography

discussed above, Hogle (1999) illustrates that the main problem underscoring popular uneasiness with organ transplants in Germany was the concern over body commodification and human rights. Against this, writes Hogle, the paradigm of free donation, and the ideals of mutual solidarity and altruism it is associated with, contributed to re-imagine body politics as a site of national reconciliation and a means to heal the relationships between citizens and the state (*ibidem*).

As ethnographies on non-western societies remind us, however, such notion of the gift is far from universal. One of the most recurrent explanations for the scarce popularity of organ and tissues donation in Japan, for example, is that the ideal of anonymous donation associated with the gift of life contrasts with local practices and notions of gift-giving (Lock 2002; Sasaki 2008; Tomomatsu 2011). Japan is a country with a flourished gift economy, and the exchange of gifts plays an integral role in commemorating key moments' in people's life and special occurrences. The gift of money and objects normally accompanies life-cycles events such as weddings, births, and funerals, as well as traditional festivities like Girl's and Boy's Days[8] and the Shichi-Go-San Festival[9]. Gifting objects is also common practice on more mundane occasions, and the Japanese have specific categories to distinguish for example the gifts to be exchanged upon returning from trips (*omiyage*), when visiting someone's house (*temiyage*) and at cyclical times during the year (*oseibo*) (Daniels 2009).

Along with these, Western-inspired festivities have also become well-established occasions to exchange gifts among friends (birthdays), lovers (Christmas) and co-workers (St. Valentine's Day and White Day).[10] Furthermore, gifts were also commonly shared with the household dead as people presented them in front of the *butsudan*, along with the offers of food and incense that the living normally make to the ancestors (Smith 1974, see also Daniels 2009). On these occasions, gifts are either exchanged or made/received in the anticipation that they will be repaid with appropriate counter gifts (Befu 1968). In this manner, gift exchange is used to mark and

[8] Annual festivities celebrated in March and May.

[9] Traditional festivity celebrating the third, fith, and seventh years of age.

[10] On St. Valentine, female co-workers gift small present of chocolate and sweets to their male colleages, who reciprocate on White Day.

reproduce both social relationships and cosmic orders (Befu 1968; Rupp 2003; Daniels 2009).

Anthropologists have thus highlighted that the principle of anonymous, selfless donation advocated by the 'gift of life' fits unwell in a context like Japan where gift-giving is a practice that places the person's within his/her significant networks of social relationships (Lock 2002; Sasaki 2008; Tomomatsu 2011). People in my field were sometimes keen to specify that this well-known argument doesn't imply that "the Japanese are not generous". The reason behind the scarce acceptance of the metaphor of the gift, their comments suggest, is not the unwillingness to give to strangers. Rather, as discussed in relation to brain death, the problem is in the moral obligations towards one's significant others, particularly the ancestors, and the fact that that they run contra the ideal of donating to anonymous strangers.

Sasaki thus explains that at the inception of organ transplant in Japan in the late 1990s, after the legalisation of brain death, professionals in the field of transplantation tended to avoid the Western trope of the 'gift of life' (2008). Instead, the metaphor of the 'relay of life' seemed to hold sway in media and popular accounts of the first case of organ donation from brain dead in the country in 1999 (*ibidem*). Sasaki argues that the image of the 'reply of life', which accompanied the pictures in the news of the organs being shipped to different parts of Japan in record-time, conveniently glossed over the procurement of organs from the dead drawing attention on the technological innovations that enabled life to be transferred and resuscitated (*ibidem*).

The imagery of the 'rely of life' had not fallen in disuse at the time of my fieldwork, especially among patients of an older generation, but other languages and metaphors were also popular. The phrase '*zōki teikyō*' (organ donation) was used in the medical jargon, scholarly literature, professional jurnals and media reports, as the most neutral, and rhetoric-free expression to describe organ procurement. The metaphor of the 'gift of life' was also commonly used, either in its Japanese version, '*inochi no okurimono*', or in directly borrowed from English as '*gifuto ofu raifu*'. Distinguishably associated with a pro-donation discourse, it was normally found in promotional campaigns and educational materials from the Japan Organ Transplantation Network and

other patients' groups. Particularly notable compared to the situation described by Sasaki was language and contents of media reports. Despite the strict privacy that surrounds donor families in Japan, their testimonies about confronting the dead of a loved one and opting in for organ donation no longer seemed to be considered too sensitive, problematic or disturbing. In fact, the JOTNW and recipients' groups were all but shy in collecting the experiences of donor families, and these also appeared in the general media framed in a way that unmistakably associated them with a positive discourse on organ donation. In describing their decisions, Japanese donor families often resorted to the same imageries associated with the 'gift of life': the will of helping others (*yaku ni tatsu*), and the hope that the donor will live on (*ikitsudukeru*).

Writing about North America, where these imageries originated, anthropologists have noted that the promise of achieving transcendence through donating oneself (Joralemon 1995) and 'recycling' life itself (Sharp 2006) is amply used to promote organ donation. There imageries, in turn, are heavily drawn upon by donor families. For them, the hope that their beloved will live on through the donated organs constitutes a key motivation to decide to donate (Sharp 2006), along with the will to construct meaning out of a tragic death by turning it into a last occasion for the deceased to be of help to someone else (cf. Lock 2002).

The anthropological analysis of the 'gift of life' has drawn attention to the ideological uses of these clichés to promote organ donation among the public. Anthropologists have highlighting how the rhetoric of the gift capitalises on people's emotional investments while actually mystifying the reality behind organ donation: the intrusiveness of organ procurement surgery (Sharp 2006), the intense harvesting of organs (Hogle 1995), the attending reification of the donor's body (Scheper-Hughes 2005), and the obliteration of the donor's identity by means of anti-rejection drugs (Joralemon 1995).

Furthermore, anthropologists have highlighted the paradoxes and inconstistencies of the gift metaphor. Sharp (2006), for example, describes how donor families are encouraged to imagine that their gift will help someone in need, while on the other hand recipients are advised to think about the new organ in de-personalised and almost mechanistic way to avoid identifying with or feeling indebted to the donor. She thus criticised the imagery of solidarity

associated with the metaphor of the gift, pointing out how in fact donor families and recipients are prevented from sharing anything more than anonymous letters, as organ donation is managed confidentially from third-party gatekeepers like transplant coordinators and medical professionals, and further argues that the paradigm of anonymous donation doesn't leave space for individually commemorating the donors (2006). The gift metaphor, Sahrp points out, conceals individual stories behind generic ideals of solidarity, which too easily overshadows the sacrifice and suffering of donors and their families (cf. Scheper-Hughes 2000).

As her critique suggests, the donor's identity is a delicate question with regard to the use of body spare parts. Differently to other body tissues, such as sperm or eggs, organs are non-reproducible, unique body parts. They are vital, and often procured from people who suffered a tragic death. Unlike blood and plasma, they cannot be separated or processed into sub-components, and are used for the only purpose of being allocated to individual patients whose luck to receive one depends on a good match with the donor. While the donation might be anonymous, the organs carry with them a lot of the (real and imagined) identity and personal story of the donor.

Anthropologists have thus variously noted that despite the rhetoric of selfless gifts, in fact, organ donation is often perceived and experienced as a highly personalised relationship between the donor and the recipient. Sharp (2006), for example, describes how both recipients and donor families fantasises about the age, gender and background of the person who donated/received the organs. Some recipients even report changes in tastes and personality after the transplant and view these as been passed on from the donor (Sharp 1995, Tomomatsu 2011, Yamazaki 2011*b*). As my interviews confirmed, Yamazaki (2011b) notes that Japanese recipients often talk of the donor as a presence who is always by their side, to whom they owe a special gratitude and whom they think of when they struggle to cope with the harsh regime of anti-rejection drugs, the side effects of medication and the health problems that often characterise the post-transplant life (see also Tomomatsu 2011).

Ethnographies of the transplant community in North America highlight how these experiences are often silenced in the public account of organ

transplantation (Sharp 2006; Siminoff 1999). At the same time, patients are educated to feel grateful and people can feel pressured to get involved with promoting organ donation out of a sense of indebtedness (*ibidem*). Anthropologists have thus illuminated that, differently to the rhetoric of selfless donation, organs are gifts that bind, and this characteristic is too often exploited to redirect moral obligations not to altruistic donors but to self-interested medical professionals (Ben-David 2005).

From the 'burden of gift' to the problem of body reification, the anthropological literature on the gift has illuminated many important aspects of the workings of transplant technology. The concept of the gift has served to map how symbolic representations have enabled the development of organ transplants and how they are appropriated and elaborated upon by the people more closely involved in it. Through such contributions, the literature on the gift has elucidated how the technology of transplantation has shaped new forms of subjectivity, social relationships and conceptualisations of the body and personhood. Maybe the most significant contribution on the theme of the gift, if not for its relevance to social theory for its influence on public opinion, is its application to the analysis of the political economy of body parts.

Titmuss's '*The Gift Relationship*' (1970) has become a paradigmatic reference in the debate on organ and tissue donation. Titmuss's landmark research compared the UK regime of free blood donation and the USA procurement system, which operated through both voluntary donation and different forms of financial incentives and commercial remuneration (1970). Analysing the composition of the donor pool, the motivations of donors and data about the quantity and quality of the blood collected, Titmuss strongly argued for the financial, medical and moral superiority of the gift over the market (*ibidem*). He showed that systems relying on financial rewards spend more on blood collection and are more prone to shortage, whereas a regime of free donation guarantees a better supply at a lower cost (*ibidem*). Moreover, Titmuss argued that financial incentives attract at-risk donors in need of money, resulting in higher chances of blood infection and disease spreading –a point tragically proven right by the blood tainted AIDS scandals in the 1980. Finally, drawing on Mauss's argument, Titmuss argued that the gift relationship is constitutive of

social bonds, and warned that the introduction of a market economy in a social sphere thus far domain of gift-exchange would corrupt these relationships (*ibidem)*.

Titmuss' book proved an incredibly influential. Not only his view of free donation vis-à-vis the market extended from blood to organ and other tissues donation, but it also crystallised in the general discourse and the scholarly debate. His argument hasn't been immune from critiques, and economists in particular have devoted no small effort to attack Titmuss' argument against the inefficiency of the market.[11] While probing Titmuss' argument, however, these critiques do not really challenge the basic assumptions at the core of his work: the distinction between free gift and the market. Social scientists and anthropologists, on the other hand, have recently taken on the problem work from a different angle, arguing that Titmuss' most significant contribution -that modes of exchange created social orders and forms of polity- was lost as its argument enjoyed such popularity that it became normative.

*The gift-commodity framework: a critique*

The gift-commodity dichotomy has attracted increasing interest in anthropology in recent years, as a growing number of scholars have questioned the value of relying on pre-defining analytical categories of inalienable, personal gifts and impersonal, interchangeable commodities (Osteen 2002). Integrating these insights in the debate of organ and tissue donation, scholars have highlighted the theoretical limitations of applying the gift-commodity framework to the analysis of the circulation of human body parts (Walbdy and Mitchell 2006; Yamazaki 2009, 2011*a*).

Key in revisiting the gift-commodity dichotomy is the well-established anthropological argument that such distinction is not built into things themselves as the same object can change status throughout its life (Appadurai 1986). Japan offers a case in point. In Japan, money is one of the most common forms of gifts (Rupp 2003), and objects exchanged in traditional gift occasions are commodities purchased with cash and chosen for their value as goods for

[11] See McLean (1986) for a review.

consumption, such as food and household goods (Daniels 2009). Daniels (2009) argues that these Japanese gifts challenge the notion of the inalienable gift that retains the spirit of the giver. These gifts are stripped off the exclusive link with the giver and their value is in the utilitarian consumption by the recipient, who is not supposed to keep them as a token of the donor but to use them up (*ibidem*). At the same time, however, gifts always demand counter-gifts and reciprocity is essential in gift-exchange in Japan (Befu 1986). The Japanese gifts thus complicate the classical assumption that commodities are not construed in view of the social relationships they embed, showing instead that even though they are alienated from the giver, commodities can create social relationships when they are part of networks of obligations and reciprocity (Daniels 2009).

Drawing on this point, social scientists have argued for the need to investigate not only how organs and tissues are construed at the level of symbolic representations, but also how they embody and are invested with meanings through the networks of exchange and circulations that they are caught up with (Weldby and Mitchell 2005). For example, through describing how organs and blood are sourced, processed and distributed by USA procurement agencies, Haley (2006) has shown that personalised gifts imbued with the spirit of the donor are part of an economy in which body parts are managed through a logic of rationality and efficiency that effectively turns them into interchangeable, uniform goods.

A crucial implication of rethinking the distinction between gift and commodity is therefore the need to revisite the moral connotation associated with these categories. Titmuss's strong argument that the market economy is disruptive of social relationships indeed informed much the anthropological denounce of illegal organ trade, as anthropologists have shed light on how the commodification and fetishisation of the flesh exposed sellers to incalculable violence, suffering and shame (Scheper-Hughes 2005). At the same time, however, ethnographic insights show that the de-humanising practice of kidney selling is also a practice through which people reassert social relationships and their place within them in contexts of extreme indebtedness (Cohen 2003). Cohen has thus illustrated that for people who resort to selling one kidney to try

and repay debts, exchanging one's body part for money is sacrifice to protect their families, and retaining their role in relation to significant networks of relationship (*ibidem*). On another axis of analysis, however, the same transaction also means obliterating the seller's social persona and turning it into bare flesh (*ibidem*). Cohen thus questions standard bioethical arguments in favour or against organ selling for not considering relevant information, such as data on health complications for both sellers and buyers, the impact that the money people can earn from selling kidney has on their financial situation in the long run, the structural conditions of their indebtedness (*ibidem*), and argues that bioethical reasoning should look beyond the moment of exchange itself to include the broader conditions in which it takes place (*ibidem*).

As his argument suggests, the circulations of human organs are part of complex networks that the gift-commodity framework is poorly equipped to describe. In particular, social scientists have drawn attention to the need of rethinking the gift-commodity distinction in relation to the increasingly globalised reality of today's public health (Waldby and Mitchell 2005). From the growing investments in public health development programs among vulnerable populations, to the expanding phenomenon of wealthy patients seeking better care overseas, problems that concern individual and collective health are often negotiated on a transnational scale where altruistic donation and the logic of the market are entangled with each other. The stories presented below about families raising money to pay for a transplant overseas, for example, are one instance of increasingly common charitable initiatives launched to support patients that turn to treatment abroad to bypass national scarcity and/ore regulations. Where Titmuss's gift relationship was conceived along the lines of national communities and welfare systems, these forms of charitable donation present a very different scenario. The communities created around these donations are those of patients and their caregivers, who often support each other in organising and managing the fundraising; while for donors the lack of identification with the recipients (whose story and needs are extreme and rare) is the drive to help. Donors and recipients do not necessarily use the gift to cement mutual obligations, and certainly do not act collectively toards the state as a health care provider. Quite at the contrary, while inspired by ideals of

justice and fairness, in reality these forms of solidarity are aimed at helping some to access treatment options that often unavailable to most people. As these cases show, the logics of altruistic donation and the market are not mutually exclusive and do not occupy separate social spheres.

*The Moral, Political and Informal Economies of Japanese Organ Transplants*

The critique of the gift-commodity indicates clearly that the spheres of the 'social' and the 'economic', treated as alternative and even opposite in Titmuss's classical theorisation, are in fact not separate, and that the 'economic' itself is instead a realm of social investigation. A well-established argument in anthropological theory, the point is still largely ignored in the classical bioethical discussion on the contemporary uses of body parts for medical research and practice. Incorporating these insights in the analysis of organ and tissue donation, scholars have thus proposed to move away from the gift-commodity and adopting the concept of economies as better theoretical concept (Waldby and Mitchell 2005, Yamazaki 2011*a*).

Drawing on these recent developments, I chose the concept of economies as a framework through which to analyse my ethnographic data. From this perspective, I describe how the global technology of organ transplants was reassembled in Japan by mapping the circulations in which organs are caught up. I do not focus on organs only, but look more broadly at the dissemination of discourses, the sharing of resources, the mobilisation of feelings. For this reason, while the chapters don't necessarily deal with these concepts separately, for clarity of analysis I talk of moral, political and informal economies to identify interrelated but different aspect of the problem.

The concept of informal economy, by which I refer to health-oriented economic transactions that take place outside of the framework of institutionalised systems of care provision, serves me to draw attention to the role of financial resources in accessing care. An important part of this thesis is the analysis of the phenomenon of the transplant overseas (*tokō ishoku*). These transplants blur the distinctions between altruistic donation and self-interest market

transactions, presenting a case where gifts can be accessed only through money and money itself become a donation to express solidarity. In analysing the problem of *tokō ishoku*, I thus start from describing the informal economies behind this quest for care, as I observed it during my experience of participating to patients' fundraising in Tokyo.

As the ethnography shows, affective resources are as key as financial ones to these fundraising. Throughout the thesis, I thus use the concept of moral economy to look at the "the production, distribution, circulation and utilisation of moral sentiments, emotions and values, norms and obligations" and how they shape the relationships between people and the technology (Fassin 2005). Challenging the idea of the technology as value-free and self-explanatory, I tease out the moral values that are built into it, and show how they shape people's experience of illness and treatment. I discuss how people's mutual obligations orient clinical decisions that concern one's significant others, and how they shape the broader public discourse on donation and transplants. I thus tease out how mutual obligations have been negotiated in Japan where, as seen, the reciprocity of the gift emerged as a crucial problem. From this perspective, I look at how people harness social relations of indebptedness to access limited resources and to create new arenas for civic engagement and democratic debate.

Lastly, I talk of the political economies of organ transplants in referring to the legal, ethical and medical systems for managing, sourcing, and allocating organs. I follow in particular the evolving of the Japanese debate on brain death in relationship to emergent forms of patients' sociality and claims for care. I interrogate the consequences of local political economies of organ donation and transplants for individual and collective health, their implications for social justice and individual subjectivity and their role in shaping imagined communities.

I am interest in how people negotiate individual and collective decisions on life and death through the way they circulate material, symbolic and emotional resources. Throughout the ethnography I thus ask who people share with, to what extent the obligation to give goes, whose interests in someone's life are

recognised. Through attempting an answer to these questions, the thesis wants to contribute to the current bioethical debates on organ transplants by showing how people in Japan have negotiated the emergent quest for organs with the long-lasting dilemmas surrounding the definition of death.

## Methodology

*Working with Biosocial groups*

To explore ethnographically such a vast topic as the situation of organ transplants in contemporary Japan, I begun with looking at the experience of recipients and their families. My preliminary research for this project focused almost exclusively on the question of patients' experience and the investigation of patients' groups in Japan, and before starting fieldwork I had also took contacts with a Tokyo-based group (JASOT)[12] to explore the possibility of joining them as a volunteer and develop an extended case study around their work. As fieldwork unfolded, the experience of transplant patients I begun to collect became the point of entry into a wider investigation that came to involve patients' families and clinicians as well. The life histories and experiences of patients remain at the core of this thesis, albeit they presented research questions I had not anticipated before fieldwork.

One of the first episodes that happened during my fieldwork was the traditional Ginza parade. Conveniently scheduled only a few weeks after my arrival in Tokyo, the traditional public event by the Japanese Transplant Patients' Association presented the ideal occasion to be introduced to the scene of transplant patients' groups. The organisers of the event belonged to different patients' organisations and were all associated with the Network of Transplant Patients' Groups, or *ZōiRen* (from *Zōki Ishoku Kanja Dantai Renkaku Kai*). The Network was an umbrella organisation funded more than thirty years earlier as a point of coordination among different, smaller associations involved in the lobby for the legalisation of brain death and organ donation in the country. After

[12] All names of people and organisations are anonymised.

playing a decisive role in the 2009 reform of the Act on Organ Transplants, the organisation no longer hold regular meetings and the Ginza Parade was to be last of their annual events.

The logistic organisation of the Ginza Parade was for the best part the responsibility of the Japanese Organ Transplant Recipients Association (JOTRA). The group was the largest in the country and one of the first to be established in the early 1990s, when cadaveric donation was not yet legalised in the country and only transplants from living related donors were possible. Some three decades later, as the number of transplant recipients in Japan had grown and information on treatment was more easily available through fellow patients, the internet an educational campaigns by the JOTNW, formally joining a patients' group was no longer the privileged way for candidates, recipients and their caregivers to receive counsel and support, and JOTRA mostly comprised middle-aged people from the first generation of organ recipients. The association, however, was still one of the most active subjects in the scene of patients' organisations, running seminars and public events to raise awareness on organ donation and transplants.

Other organisations involved in this sort of activities included groups of sufferers of a particular disease. The Association for Children with Cardiac Disease, the Association of Children with Bilary Distresia and the National Association of Kidney Recipients were all associated with the issue of organ donation and transplantation, even though, in the words of one of my informants, this was not their priority. Organisations of these sorts offered support to people suffering from diseases that could present varied degrees of severity and chronicity, and for which a transplant was not necessarily the only treatment available. The groups associated with *tokō ishoku* patients, on the other hand, worked with people for whom transplant was the last and only chance.

Along with the single fundraising groups that family set up to collect money for the operations, two associations existed that specialised in offering support to parents of young patients who decide to travel overseas for a transplant: the Japanese Association in Support of Organ Transplants (JASOT) and the Network for International Transplants (NIT) Japan. The families I worked with had been involved with both organisations. One of my interlocutors, who was

still very close to people at NIT, firstly introduced to the group's leader, with whom I conducted interviews about his experience of transplant advocacy dating back to the early 1990s. I also followed a fundraising that organised by JASOT, and participated as volunteer to various events run by the organization during my time in Japan.

Most of the recipients and families I met at the Ginza parade were not formally affiliated with any particular organisations, event though they took part to various initiatives promoted by different groups. Rather than focusing on one single group in particular, I thus followed patients' individual cases in depth. The Ginza Parade offered in this sense an important occasion to recruit participants for this project, because it enabled me to get in touch with patients and their families directly without having to relying on gatekeepers such as medical doctors, transplant coordinators or even patients' groups leaders.

I anticipated that asking medical doctors or even leaders of patients groups to introduce me to transplant recipients could significantly influence how people would see me and even whether I would have been able to meet some patients at all (Hirano 2008). In particular, I wanted to avoid sourcing participants through transplant programs, as I expected that in a context like Japan, where the doctor-patient relationship is particularly authoritarian and patronising, relying on gatekeepers would greatly condition my interactions with possible participants. More generally, I did not want people to feel pressured into participating in the project out of a sense of obligation towards third parties.

While I expected that pastoral figures like medical professional might have a very protective and even patronising attitude towards patients, I also had my own fair share of concerns about the potential intrusiveness of my research. Given the ethically sensitive nature of the project, I anticipated that people could have considerable reservations about disclosing personal information concerning their health and medical history. In Japan, people are reluctant about revealing one's medical condition and talking openly about chronic and severe illness. Disability can be strongly stigmatised, and people are comprehensibly cautious about disclosing details about health and treatment. In the case of organ transplant in particular, the problem of privacy is further exacerbated by the controversial public debate on this technology and by the

intense media exposure that accompany the fundraising campaigns. As confirmed by some of my interlocutors, the decision of listing for an elective and highly contested treatment like transplant can attract unwanted judgement and scrutiny from strangers, meaning that some people are all but keen on sharing their medical history.

Questions of representation were also closely related to ethics of sourcing informants. As the ethnography below will make clear, negotiating health is an important aspect of the experience of becoming a transplant recipient. While recipients are tied to medication and follow-up visits for the whole of their post-operative life, many of them do not self-identify as patients for the negative connotations that the term implies. I thus expected that people would have a variety of different understandings of what it means to be a transplant recipient, and that to some this might not be a distinctive or important part of their persona. Thus, I wanted to work with people who were not only confortable in sharing their experiences with me, but also self-identify as transplant recipients. I did not want to super-impose on people labels they dismissed or even rejected. Equally, I did not want to be intrusive or confront people with question concerning their medical history if disengaging from it was a way for them to negotiate notions of health and normality.

For these reasons, the Ginza parade offered the perfect occasions to meet people who self-identified as transplant recipients and were willing to go public about their experience. In fact, many of the people I met that day were not organ recipients themselves, but parents of young children who had applied for or received a transplant overseas. For the reasons just discussed, I decided from the very early stages of my fieldwork not to involve young patients directly. Even though people never explicitly objected to the possibility, it was clear from their recommendations to me as well as from the way they talked to each other in the presence of children that they were particularly careful to avoid children were directly confronted with discussion that could evoke traumatic events or making them aware of potentially problematic implications of their condition. I respected these boundaries and conducted interviews only with parents. This, in turn, provided insights to rethink who we are talking about when we talk

about transplant recipients and whose lives and relationships are at stake in the process of becoming an *ishokusha*.

I knew before starting fieldwork that doing research on organ transplant can strip the ethnographer of her best-established tools of investigation, for there are quite obvious limits to participant observation. As I found out, working with biosocial groups also presented distinctive challenges. In my case, having direct access to people during the pre-operative phase proved unfeasible. For paediatric patients in need of a heart transplant and their families, the months leading to the decisions of listing for the operation are often extremely critical. The child is often hospitalised in severe conditions and quite understandably both medical professionals and other patients are very protective of the family's privacy at this stage.

It is only when the family decides to pursue the transplant overseas that the fundraising forces them to go public. During the time of my fieldwork, I was able to follow two cases of fundraising. In one instance, I was able to participate to the campaign myself and had closer access to the family, which allowed me to also visit them at the hospital. In the other case, instead, access to the family was mediated by the organisation that was helping them in running the fundraising. For this reason, as well as for the particularly critical condition of the patient, meeting them or visiting at the hospital proved unworkable.

Even with my main informants, who applied for the transplant years earlier and had all returned to a quitter life, daily interaction was not always possible. These dynamics, on the other hand, reflected the nature of the group of people I worked with. My interlocutors identified themselves as belonging to what could be called a biosocial group, by which I mean a group of people who share a common medical history/condition and who participated in forms of sociality informed by this aspect of their lives. People did not belong to a geographically bound community that could be clearly accessed, nor they engaged in daily activities together that I could participate to. These factors greatly influenced the methods I adopted as well as my positionality in the field. Before dealing more in details with these questions, however, a note is due to introduce the main participants to this project.

*The main interlocutors*

The Ishokusha

The people I met at the Ginza Parade became some of my main interlocutors. Overall, I interviewed more than fifteen among transplant recipients and their families, including families of young children who had applied for the transplant in recent years and patients who belonged to an earlier generation of organ recipients and, in many cases, had been involved in the issue of transplant advocacy for more than two decaded.

Within this last group, two of my closest inerlocutors were Nakamichi-san and Komeno-san. Nakamichi-san was an organ recipient himself and at the time of my fieldwork he had been serving as head of the JOTNW for two years, after stepping down as leader of the JOTRA, which he had chaired for more than twenty years. An old friend of his, Komeno-san also had a decades-long history of transplant advocacy. He joined a transplant patients' groups in the 1990s, after his son had become one of the first Japanese children to receive a heart transplant in the U.S, and at the time of my research he served as an external member of the Ministry of Health and Welfare special committee on organ donation and transplantation.

The two men were among the best-known figures in the movement for the legalisation organ donation from brain death. I met with them several times during my fieldwork, for individual interviews and on the occasion of informal gathering with other patients. Through them, I was also introduced to other people, both organ recipients and medical professionals, who joined the movement for the legalisation and promotion of organ donation in Japan. Their long-term engagements with the issue of organ donation and transplantation offered me a privileged perspective into the theme of transplant advocacy, while also providing valuable insights into the experiences of early patients and the similarities and differences with the stories of patients from a later generation.

The people I worked mostly with were the families of young children who had applied for/received a transplant overseas in recent years, in particular five

families who travelled to North America between 2006 and 2009, when their children were between one and nine years old.

The Satos and the Arais were from Tokyo. Sato Sayaka and her husband Juntarō both worked in the media industry, and their daughter was in her teenage years at the time of my fieldwork. Arai Yoshinori, a *salaryman* in his forties, and his wife, a professional housewife, had two children. Nakajima Mariko was a single mother of three, and lived with her family in an inner province of Japan some two hours by train from Tokyo. Kumano Natsuko and her husband Keisuke lived in Yokohama, the major town neighbouring the capital. A young *salaryman* and a nurse, they had travelled to America to get their first child on the list for a heart transplant when he was only one. Ota Yuka raised her only child without his father. She was from a wealthy family from central Japan, and run her own business between the capital and her hometown.

Despite living in the Tokyo area, the Satos and the Kumanos referred to a transplant program in Osaka, while the other families were based at a medical centre in the capital. Osaka and Tokyo are the two cities in Japan where transplant programs are based that have the highest concentration of patients, and the majority of patients who receive a transplant overseas refer to physicians and surgeons from these centres. Accessing care depends on the possibility of being referred to these medical facilities, but the composition of *tokō ishoku* patients is not at all limited to families living in large urban centres. Fundraising campaigns are run also in more remote provinces and patients from all different geographical provenience travel overseas. What determines people's capacity to purse care in a foreign country, however, is the possibility of being referred to medical professionals in Japan who have the right professional connections abroad.

Another major factor that determines people's possibility to receive care overseas is the burden of the after-care. While the costs of the operation are for the best part met through the fundraising, the follow up care can be very challenging for families. The costs of anti-rejection drugs are partly covered by insurance programs, but the financial burden remain challenging for many people. In addition to that, the after-care can present a series of complications.

Families for example have to be able to afford regular leaves from work to accompany children to periodical follow-up visits at the major transplant centres in Tokyo and Osaka. When people have more than one child, they must be able to rely on solid family and social networks to assist the young patient during the time s/he is hospitalised while also ensuring care to his/her siblings. The sample of people who participated to this study suggests that the option of the transplant overseas in Japan is not necessarily for the extremely wealthy; nevertheless, *tokō ishoku* does remain an elective treatment, which is feasible only when families can afford to pull out considerable social and financial resources.

For these reasons, the life trajectories of the people who participated to this research are not to be intended as sociologically representative of how the average Japanese citizen would access treatment. Neither they want to be fully representative of the more general experience of becoming an organ recipient, as the cases of paediatric *tokō ishoku* are very specific and different to other types of transplants.

Thus, the case studies discussed, both those of transplant activists and *tokō ishoku* families, are in no way representative in a sociological sense of the experience of Japanese organ recipients at large. They are, nevertheless, telling of how this experience is lived and embodied, as well as narrated and made sense some of. As it draws on the experiences of a peculiar sample of people within the wider group of organ recipients, the ethnography below is indicative of problems that are specific but also of broader relevance.

First of all, it provides insights on the experience of people who self-identify as *ishokusha* and whose life trajectories got significantly entangled with the problem of organ donation and transplants in Japan. While certainly not all organ recipients share this view or dedicate their free time to transplant advocacy, the stories of the people who have done so shed some light on the emergence of new forms of health-related subjectivity in Japan and on the ways in which people's civic engagement on these matters contributed to reshape notions of life and death in relation to transplantation.

Further, while different to other types of transplants, the case of paediatric *tokō ishoku* presents an extreme instantiation of issues of larger significance. The

young age of the patients, the severity of the condition and the exceptionality of treatment contribute to make the stories of paediatric *tokō ishoku* particularly critical cases. These very factors that cast them apart from other types of transplant, however, are also those that best tease out the moral predicaments built into organ transplantation, in particular the denial of mortality and the imperative of saving lives at any costs. The emotionally tense and dramatic stories of *tokō ishoku* families, therefore, speak of how these problems articulated in Japan, revealing the tensions between the ever-enduring legacy of the brain death problem and the increasingly pressing problem of organ shortage.

## The Clinicians

While I initially intended to focus exclusively on transplant recipients and their families, which has been largely overshadowed by the interest in the brain death problem, halfway through my fieldwork I realised that the issue of death and organ donation was a necessary part of the story I wanted to tell. The tensions between the dilemmas surrounding death and the imperative to save life that the stories of my interlocutors revealed were far from settled at the time of my fieldwork. Almost two years after the enforcement of the new law on brain death that my informants had been advocating for, everybody's attention was on whether the new policy would have had an impact on increasing the national donation rate and to what extent. The much debated issue of brain death, which I had resolved not to go back to, kept on coming back in how people framed the problem as one that still needed to be worked on.

In tackling this problem, I started by conducting research on the literature available in Japanese language (Aita 2012; Uryuhara 2012), and started to recruit potential informants among clinicians working in intensive and emergency care. Personal connections proved extremely useful in this case, as in most cases I couldn't contact medical doctors directly. Through one of my interlocutors, I managed to contact Dr Kitanaka, whom I met at one meeting on organ donation at the very beginning of my fieldwork. Through him, I also

managed to have the contacts of other clinicians he suggested might be worth interviewing. Further, I searched on medical journals for authors who seemed to publish on the question of brain death and organ donation, and asked informants in the JOTNW to introduce me to clinicians who were collaborating with them.

I thus managed to interview seven among neurosurgeons and neurologists working in intensive care units across the country. Again, the sample of interlocutors doesn't want to be sociologically representative of clinical practice more in general. Quite at the opposite, the people sampled are a minority of medical professionals actively involved in the debate on brain death, end of life care and organ donation. While the prominence of brain death in the public debate means that the majority of Japanese physicians are reluctant to openly disclose the condition to families and discuss organ donation, the clinicians interviewed for this study were selected because they proactively support organ donation (two out of seven interviewees) and/or advocated for full disclosure of information to patients' families, including in cases of brain death.

Given the strict policies protecting patients' privacy and the limited time of my fieldwork, it was not possible to negotiate access to the clinical ward, let alone witness a case of organ donation, which cannot be scheduled. The experience of patients' families is therefore not part of the ethnography, and would have required a completely different research. The interviews presented are not to be intended as a comprehensive description of what goes on in the clinical setting. Instead, they want to elucidate how medical categories are constructed as people negotiate the meanings and uses of the diagnosis.

The reluctance of medical professionals to discuss the prognosis of brain dead patients and broach the issue of donating organs with the next of kin has been traditionally indicated as one of the main causes behind the chronic shortage of organs in Japan. The interviews thus want to represent a very specific position within the general landscape of Japanese clinical practice concerning end-of-life care, one that illuminates the ways in which people negotiate the tensions between the problem of brain death and the mounting pressure to organ procurement on the clinical setting.

*…and Myself*

During the time of my fieldwork, between September 2011 and November 2012, I was based in Tokyo as an exchange researcher at Waseda Graduate School of Asia-Pacific Studies. It was not my first time in Japan. Previous to my fieldwork I had lived for a few months in Kyoto and spent one year in Tokyo. I knew the city well, but also knew that Tokyo is hardly representative of the rest of Japan.

As anthropologists and sociologists have noted, standardised, homogenous representations of Japan tend to overshadow the great variety of regional differences that exist within the archipelago and focus predominantly on the country's major urban centres, particularly Tokyo and Osaka (Sugimoto 2003). These representations reproduce a hierarchical opposition between the urban core and what the Japanese call *inaka*, which literally means 'rural' but in fact encompasses everything that lies outside the large metropolitan areas in the Kanto and Kansai areas.[13]

Through my research, I met patients from all over the country. To some, living in peripheral towns, commonly portrayed as less progressive than the city, was a source of potential concern for they feared being stigmatised for their condition. More significantly, the interviews clearly indicated that the two major cities of Tokyo and Osaka, were not just the cultural, political and economic centres of the country, but also the focal points of the world of transplant medicine, where the major patients' organisations, transplant programs and medical professionals were based. Similar networks of medical doctors and patients activists existed in more peripheral centres as well (Sapporo, for example, was such a case), but were more for the best part centred in major cities and consequently people's possibiliy to receive treatment often depended on them having the resources and connections to access these city-based transplant centres.

As an anthropologist based in one these large urban cities, living in Tokyo shaped the daily practicalities of my fieldwork in ways that reflected in the production of this ethnography. The circumstances of working with biosocial

[13] The regions where Tokyo and Osaka are located.

groups were further exacerbated by the dispersive and fragmented characteristic of urban life (cf. Bestor 2003). While daily and prolonged interactions with my interlocutors were not always possible, I couldn't count on other strong social networks in the local community where I was living. Many of the people I met on a regular basis, both Japanese and foreign friends, were not related to the topic of my research. Even my Japanese friends, who knew about the problem of brain death and organ transplants through the media, viewed me as the expert. They often asked curious questions and occasionally showed surprise at the fact that I might know more than they did about a problem that in so many ways was seen as specific to Japan. To them, I was clearly an 'insider' of the world of organ donation and transplant patients' group that I was often struggling to access.

In many other ways, however, I was clearly an outsider, as my nationality and ethnicity clearly defined me as a '*gaijin*' (foreigner). As such, I was often given standard narratives that reproduced both stereotyped ideas about the differences between Japan and other countries, as well as the assumption that as a non-Japanese I must had little clue about the society and culture of the country I was temporarily living in. For example, people were often keen in explaining me why the Japanese didn't accept organ transplants the way 'westerns' do. Quite a few times I heard that "the Japanese don't like to talk about death" and see the dead body as having a special value to the bereaved family, as if these behaviours special to Japanese culture alone. Nevertheless, I rarely encounter these standard narratives in the conversations with my interlocutors, especially after our first, explorative meetings.

Most of these follow-up interviews happened with women. While I met in different occasions with groups of families, I usually had individual interviews with the mothers of young patients. As a woman, I had easier access to them and they, in turn, usually had more time to spend with me because they were working shorter hours than their spouses. This influenced significantly the kind of narratives I had access to. The mother-child bond is an important part of the construction of women's identity and subjectivity in Japan, and women are those who usually stay at the hospital with the patient while the husband takes care of the fundraising. These mothers' narratives thus offer key insights into

the strong bond between the sufferer and his/her caregivers and the experience of losing a person who is part of oneself.

I became very familiar with this group of interlocutors. Personally, I found myself at ease in collecting their stories, and at times I felt that our meetings were almost cathartic for some interviewees, especially for the mothers who had lost a child. Despite the proximity and the familiarity, however, I always remained distant from their stories. As much as I empathised with their stories, I knew their loss and suffer was not something I had direct access to having not experienced it myself. In fact, at least during fieldwork, I found that cultivating some emotionaldetachment was key to be able to carry on doing research on a problem that constantly confronted me with experiences of death.

Paradoxically, I felt more an insider to the clinicians' world, despite the fact that our interactions were sporadic, brief and much more formal than those with transplant patients and their families. Working with clinicians meant having to book appointments for interviews through personal assistants, filling in forms on ethics and information disclosure, and showing off all my knowledge of Japanese honorific forms. Despite the circumstances, and the clear divide in expertise that separated me from my neurologists-interviewees, I never felt as a complete outsider to their world, for even across our different expertise I was able to argue back and probe them on the topic of our conversation.

Similarly to what Kaufman (2006) notes about her ethnography with medical professionals and patients in American intensive care units, one of the most striking characteristic of my fieldwork was that it constantly faced me with situations that constantly shifted the boundaries between insiders and outsiders, between *uchi-soto*, as one would say in Japanese. I was an outsider to the society I lived in, but I was also studying a problem that is not culturally bounded in a traditional sense. I inhabited a reality that was distant from the supposedly 'authentic', 'traditional' Japan of the countryside (*furusato*) –the Japan that people back home often asked me about as an anthropologist who had worked in the field. I lived in a city where many are, like I was, away from the networks of family relationships (*uchi*), and had to gradually negotiated my role as an insider in the world of organ donation and transplants in Japan by navigating its standard narratives and communal events. My positionality in the

field shaped the ethnography below, as it influenced the methods that were available to me, and in turn reflects in the way the material is (re)presented.

*Data collection and Writing Up*

Interviews and Narratives

As just discussed, many of the situations I encountered in the field didn't allow me to conduct prolonged participant observation. In dealing with this condition, I worked out strategies similar to those that Steinhoff (2003) describes in her study with anti-state groups in Japan. I followed individual cases through collecting life histories and conducting in-depth interviews, and I conducted intermittent participant observation during key events.

The life histories of *tokō ishoku* families guided me through my investigation of the problem of organ transplants in Japan. I collected their stories through repeated interviews. With rare exceptions,[14] the interviews were conducted in Japanese, a language that I was quite confortable with having studied it for five years in Europe and having already lived for a long period in Japan. I always recorded the interviews and transcribed them in two separate phases. First, during my fieldwork, I wrote down extended summaries of the conversation in English. Later on in the process of writing up the thesis, I then translated literally key passages, including all the quotations in the text.

In translating them, I remained as close as possible to the original phrasing and structure. Omissions are always indicated in the text. All passages quoted together are extracted from the same interview and reported in the original order. When terms are translated that can have multiple meanings in Japanese, the original is given in parenthesis. All terms reported in Japanese are from recorded or printed materials; other phrases and words are reported as quotations only if they appeared in Japanese in my notes. To facilitate the

[14] One of my informants occasionally preferred to use in English, a language she had learned through studying abroad.

reading, repetitions have been edited in the translation when they reflect syntactical differences between Japanese and English.

The reader might still feel that the extracts from the interviews reported are at times almost too polished and 'constructed' to be 'raw material'. This is due to the nature of the material presented. The interviews with patients's families normally took the shape of long, unstructured conversations. I found that my initial questions usually served to give the space to my interlocutor to articulate long narratives structured in very similar ways to revisit key moments in the experience of becoming organ recipients. Thus, I did not use the interviews to probe subjects or ask specific questions, but to enable people elaborating and presenting their narratives. These were narratives that my interlocutors had gone through many times before, alone, with family and friends and even with strangers and journalists. Their accounts present little inconsistencies, and read instead as very structured and almost rehearsed. In this sense, the narratives are not meant to be read as 'matter-of-facts' accounts, but are used to to tease out how people make sense in their own terms of the experience of becoming organ recipients.

In analysing the material, I found that the way people talk of their experience and organise their stories highlight certain crucial nodes of meanings, which I use to identify the issues that people place significance upon (cf. Franklin 1997). I thus unpacked these nodes of meanings to see how people elaborate on aspects that are considered particularly relevant or problematic, such as reciprocity (*ongaeshi*), burden (*meiwaku*), hope and effort (*ganbaru*), normality/health (*atarimae*/*kenkō*). Further, I paid particular attention to the way in which people construct the narratives and how they situate events within broader life trajectories. Through this approach, I used the narratives to elucidate how people organise their accounts of traumatic episodes of illness and death as a way to construct meaning out of them and reconcile with the outcomes of these events (Kleinman 1988).

From this perspective, the narratives shed light on how people negotiate important aspects of their experience, revealing how they gauge delicate clinical decisions and navigate the post-operative life. Further, the narratives are indicative not just of individual experiences, but also of how these experiences

are collectively negotiated within the broader discourse on organ donation and transplantation in Japan. They are indicative people's self-awareness and reflexivity on these problems, and reflect how sharing and circulating narratives among patients and with the public is part of the eways in which people contribute to the social discourses and representations on organ donation and transplants.

Very differently to this, I used the interviews with clinicians to probe them on the discrepancies between the official protocol on brain death and donation that they all say to abide by and the way in which they actually put it to work in practice. The interviews with this group of informants were usually more structured than those with transplant recipients and framed to test specific hypotheses. All the interviews with clinicians were recorded and fully transcribed in Japanese. In analysing the material, I paid special attention to the choice of terminology, focusing on the different attributes that people attach to the categories brain death and how these determine changes with regards to clinical practice and patients' treatment. The interviews are thus used to highlight the divergences between the rationality underpinning the construction of brain death as a medical category, and the logic that informs the many possible ways in which brain death is managed in clinical practice.

Participant Observation

Picking up on the interviews with my interlocutors, I scaled up and traced the networks of patients' support groups, medical doctors and transplant professionals through which people navigate their way to treatment and on which they rely on during the post-operative life. Patients' groups and informal networks of mutual support have traditionally plaid an important role in Japan, where institutional support to the development of this field of medicine has been traditionally poor and this treatment option was viewed with scepticism even among medical professionals. In particular, patients who seek treatment abroad, have to rely on informal networks of patients and doctors to even know about the possibility of the transplant overseas.. Participating to public events

run by patients' groups and fundraisings for *tokō ishoku* patients was thus an important part of my fieldwork.

Two fundraisings campaigns were going on during the time I was in Tokyo, both running at the same time and lasting for a few weeks/month. In one case, I had the possibility to follow the case through the entire fundraising and after the operation, and also helped in running the campaign. In the other case, I had only limited direct contact with the patient's family and followed their campaign through participating to the public events run by JASOT, which helped the family organising the fundraising. These two different case studies enabled me to observe the fundraising within the broader networks of medical doctors and patients' groups that families navigate as their organise the campaign, while also participating directly to an experience that patients' families describe as particularly emotionally charged.

During my fieldwork, I also took part to various periodical events that characterise the local transplant community, including informal get-togethers, educational seminars and conferences, annual meetings of patients' groups, and the traditional Transplant Games and Running Festival organised by the JOTNW. These events bring together patients and their caregivers, medical doctors, transplant professionals and, occasionally, donor families from all over the country. They are key events through which people participate in the public discourse on organ donation and transplant in Japan, as they function to promote a positive image of the treatment and commemorate its social worth. They are also events that contribute to shape people's identity as *ishokusha,* by fostering social bounds among fellow patients and with pastoral figures like transplant surgeons. Taking part to these public events and joining my interlocutors during private get-togethers and hospital visits provided me with important insights into how people negotiate forms of sociality around their shared medical history, how they reflect on their condition by sharing private concerns and rehearsed narratives with each others, and how this aspects of their expeience inform their public engagement with organ donation and transplants.

*ONE*

# Scarcity

## Organ Transplantation as an Anthropological Problem

There is one picture that systematically features in conferences presentations, educational material, and news about organ transplantation in Japan. It is a graph showing the international rates of cadaveric organ donation. It starts with Spain, the country with the highest ratio of organ donors per population, followed by America, the real cultural term of comparison, and at the far right it ends with a column that looks more like an under-bar. With a percentage of the order of zero point something, Japan closes the line-up of international organ donation, as the industrialised nation with the lowest rate of cadaveric organ donors.

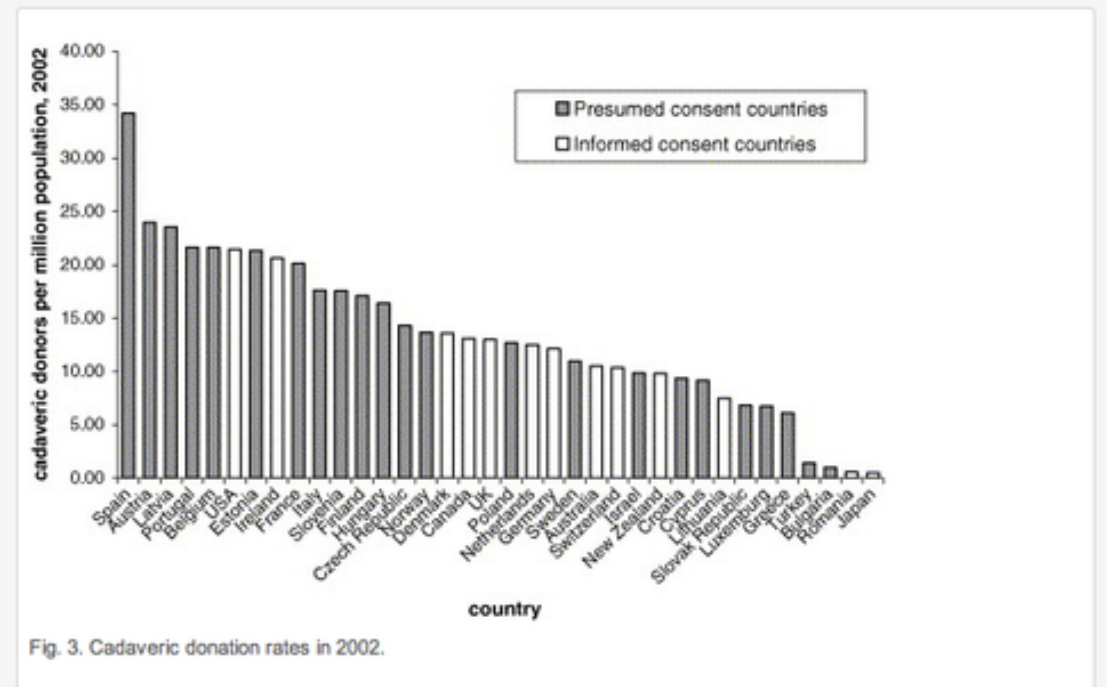


Fig. 3. Cadaveric donation rates in 2002.

Fig. 1 : From Abadie and Gay (2006).

For thirty years after the Wada transplant, organ procurement from brain dead donors was effectively impracticable in Japan, and the transplant of solid organs other than kidneys and livers, which can be procured from living-related or non-heart beating donors, remained impossible. Brain death organ donation was legalised in 1997, but it was only in 1999 that organs, including a beating heart, were first procured from a brain dead patient. Since then, brain death donations have been constantly on the rise, but data show that in the majority of cases people consent to donation only after cardio-circulatory failure (NHBD), when organs like the heart are irretrievable for transplant purposes (see Appendix 1). The statistics on transplants performed, patients on waiting lists, and average waiting times, only amplify the effect of this scarcity by quantifying its human cost, whereas the omnipresent graph powerfully suggests that such scarcity is in great part man-made.

The development of transplantation (*ishoku iryō wo suishin suru*) was the way in which people most frequently framed the situation. It draws a trajectory of a quantifiable progress, and mobilises the idea that developing this technology in practice is a perfectible enterprise. Scarcity, framed in terms of an unequal relationship between demand and supply, becomes, from this perspective, the margin of technology's malfunctioning, the gap to close, or at least to fill, in order to develop transplantation.

In this chapter, I unpack this conceptual link between scarcity and the development of transplantation. Moving between the global context to the specific case of Japan, I trace the development of transplantation and describe how I see this as a modern anthropological problem. Here, I refer to a domain in which “forms and values of individual and collective existence are problematised or at stake, in the sense that they are subject to technological, political and ethical reflection” (Ong and Collier 2005). Instead of moving from the assumption that behind the development of transplantation there lies self-explanatory scientific progress, I map how the development of transplantation – both as a historical process and as the goal of organ sharing programmes– entails a redefinition of relevant anthropological questions. From this perspective, the chapter proposes a different look at the core problem at the heart of the enterprise of organ donation and transplant: scarcity.

# Contingent Beginnings

Before becoming technically possible, organ transplant had to be conceivable. Until the seventeenth century, disease was understood in Western medicine as the result of an imbalance in the whole organism (Porter 2006). This model was radically transformed by changes in medical practice and knowledge. The development of anaesthesia and antiseptic from the late 1860s paved the way for the development of modern surgery, contributing to a renewed interest in anatomy by making internal organs accessible, observable and manipulable (Schlich 2010). On the other hand, the institutionalisation of laboratory medicine, a new way of looking at the body, began to emerge, which focused not on the structure but the physiological function of organs (*ibid.*). As Schlich illustrates, these factors produced a major epistemological shift in the conceptualisation of disease and body systems. It was this logic, which individuates pathology in the failure of a single organ that was necessary for the invention of organ transplantation between the 1880s and 1930s (*ibid*).

The concept of organ replacement as a therapeutic technique would become so powerful as to entirely reconfigure the field of surgery around the method the new treatment required, which necessitated an unprecedented degree of surgical precision and biological knowledge, as well as a "systematic approach to diagnostic, treatment, risk and outcome assessment, often blurring the traditional frontiers between surgery and other disciplines, medical and beyond" (Trohler 1993: 985). It would take several decades, however, for this to happen. At the beginning of the twentieth century, Alexis Carrel, who would go on to receive the Nobel Prize for his research, developed pioneering techniques in organ maintenance and vascular surgery, making it possible to preserve organs outside of the body and restore their function after the transplant (Hakim and Papalois 2003; Hamilton 2012). Carrel's work addressed the major technical obstacles to organ replacement, and at the beginning of the twentieth century the first successful surgical transplants were reported (Schlich 2010). Even so, the interventions inevitably resulted in clinical failures. Revascularisation allowed the functioning of the organs to be restored only

briefly and the grafts eventually died. No link, however, was established or investigated between the observed failures in organ grafts and the mechanisms of histocompatibility, even though these were already known at the time (Hamilton 2012; Schlich 2010). By the turn of the twentieth century, all the factors that would make transplant possible were in place, but in the face of systematic graft rejection the concept of organ replacement had lost its cachet in the research community and was eventually abandoned until after WWII (Schlich 2010).

In the mid-twentieth century, with the development of techno-medicine, the invention of dialysis, and the renewed interest in immunology, transplantation again became the subject of intense research and experimentation. Officially histories usually report 1954 as the date of the first clinically successful organ transplant. The intervention was performed in Boston by a team led by Joseph Murray, later awarded a Nobel Prize for what the media called “the ultimate operation” (Lederer 2008). Donor and recipient were identical twins, and the organ in question was a kidney. The combination was a common one, and for good reasons. The kidney is the ideal prototype for organ transplant, because the technicalities of the operation are simpler than with other organs. It is easily procurable from living-related donors, improving the chances of a good tissue match even in the absence of sound immunological knowledge and effective immunosuppressant drugs, neither of which were available when the first modern transplants were performed.

Immunological rejection remained the obstacle to work around if transplant was to develop into a fully therapeutic treatment on a large scale. Usually less considered is a second major problem, ischemia time. Ischemia is the process of tissues deterioration that occurs when blood supply is cut off. Ischemia time refers to the time the tissues of a single organ can survive without blood perfusion before they become unusable for transplantation. This time dictates the practical conditions of transplantation and would exert a major impact on this field of medicine, and beyond. Studies of organ maintenance had already showed, in the early nineteenth century, the possibility of retarding the process of tissue deterioration outside of the body. The implementation of new technical solutions for organ preservation and the development of communication and

transportation systems to dispatch them across long distances in a short time made it possible to develop transplantation in a systematic way. Even so, the problem of so-called warm ischemia remained, that is the deterioration of tissues while organs are still inside the body. If not perfused with blood, the organ dies; but to retrieve them before circulation is cut off would mean procuring organs from a patient who is still alive. Warm-ischemia thus posed a major challenge not just to the logistics and technicality of organ transplants, but to the ethics of medical practice as well. While the problem was easily manageable with kidneys, it became inescapable when surgeons set out to transplant the heart.

By the mid-1960s, teams of surgeons across North America and Europe had been planning the intervention in what was described as a silent competition to breach the ultimate medical record: transplant a human heart. In 1967, cardiac surgeon Christiaan Barnard caught the world by surprise by announcing the first heart recipient was recovering from a successful operation at Cape Town Hospital in South Africa. On December the second, a young woman was hit by a car, transported to the nearby hospital and brought to the intensive care unit where a neurosurgeon declared her dead. The following day, the woman was moved to the cardiothoracic unit of the same hospital, where Barnard and his team started the procedure for organ procurement. The patient was brought to the OT, and only then did Barnard himself switch off the ventilator and initiate cardiopulmonary support to restore the blood flow in the body as he extracted the heart (Hakim and Papalois 2003; Hamilton 2012). At what point did the patient really die? This was the question Barnard was confronted with by his critics.[15] The answer lies in how the complex array of resuscitative technologies, from artificial ventilation to cardiopulmonary support, was used to enable death to happen in a certain way.

[15] From the BBC Tomorrow's World Special 'Barnard Faces His Critics' broadcast in 1968.

# Organ Transplants and the (Re)Definition of Death

In 1959, two French neurophysiologists, Mollaret and Goulon, published the findings of their clinical work with patients on artificial life-support and coined the term *coma dépassé* to refer to a condition that, they stated, had never been previously observed. In *coma dépassé*, literally “beyond coma”, not only are the cognitive functions of the person absent, but even their vegetative life functions appear to be irremediably lost (1959). It is a state of life beyond life itself. Although similar findings had already appeared in medical literature, Mollaret and Goulon were the first to clearly identify what was to become known as brain death as a distinctive condition different from other comatose states (Widjicks 2011). Further publications followed the paper by Mollaret and Goulon, and through cumulative clinical data, medical experts around the world observed consistent symptoms and causes attributable to a precise aetiology. Irreversible coma became a new clinical category. It was identified as the loss of function in the entire brain, including the brain stem, which is the part of the brain responsible for the organism's vegetative functions, including breathing and the regulation of blood pressure. When the brain-stem stops functioning, the person goes into respiratory arrest, blood pressure drops and the heart consequently stops beating. Obviously, people had always been ‘naturally’ dying of brain death, but, starting from the late 1950s, the possibility of artificially suspending the process was what made brain death a possibility.

Clinical data about this new class of patient suggested that, even when treatment was prolonged, cardiac arrest was both inevitable and imminent. Physiological and biological knowledge indicated that the loss of brain-stem function inevitably leads to rapid disintegration of the capacity of the organism to sustain itself and that life-support can only briefly prolong, but certainly not reverse, the process of death of the body that follows the death of the brain. The defining of brain death, by which I mean the artificially created possibility of ‘suspending’ the process of dying by means of artificial life-support, faced clinicians with a radical shift in the conceptualisation of the role of medicine itself. From the 1950s, the development of intensive care, and in particular the

use of mechanical ventilation, made it possible to stabilise critically injured patients, who would have otherwise died immediately, and sustain them throughout the process to a full recovery. With these advancements in resuscitative and life-support techniques, however, came also partial clinical successes: conditions suspended between life and death that were beyond the point of recovery but could nevertheless be artificially prolonged (Kaufman 2000). Death, in these cases, would occur only by the active withdrawal of life-support treatment. Physicians were no longer charged with confirming that the person had died, as they are called upon to verify the decease after cardiac arrest, but were faced with unprecedented questions about where the line should be drawn between letting a person die and killing a patient, and who has the right to decide (Namihira 1988). Medicine became the gatekeeper of contemporary death, shaping when, where and how people die (Kaufman 2006). Further, as attested by the on-going debate about the right to die and assisted suicide, these clinical decisions increasingly escaped the domain of the hospital and came to assume great relevance as problem of wider social concern at the interface between medical knowledge and legal regulation (Rothman 2003).

The dilemma over the new condition of brain death was further exacerbated by the fact that, with the concomitant development of intensive care and transplantation medicine, the new class of patients treated in the ICU had become the ideal source of organs for transplants. Brain death produced bodies that could be taken as dead persons while still being kept biologically alive. Conveniently enough, it offered a safe way out from the ethical impasse of how to procure fresh organs from the dead without ‘killing’ the donor. Moreover, enabling death to happen in a clinically controlled manner provided an outlet for managing organ procurement in a systematised way, allowing time to obtain consent from the next of kin, select recipients, and arrange for organ retrieval and transplant.

Regulations were needed. The validation of agreed diagnostic criteria and protocols for clinical practice became necessary to provide physicians with clear ethical guidelines for end-of-life care, as well as to avoid medical professionals who engaged in the practice of organ donation being charged with murder. The

first attempt to stipulate such a regulatory framework was the notorious Ad Hoc Committee of Harvard Medical School. Formed in 1968, the committee was charged with defining the new condition of 'irreversible coma' (brain death) and indicating solid diagnostic criteria and tests to determine it in practice, in order to provide standard guidance to clinicians and avoid ethically sensitive decisions being made at the discretion of individual physicians (Belkin 2014). After carefully considering the ethical aspects of the case, the committee concluded that the diagnosis of brain death was to be taken as a reliable and sufficient indicator to discontinue medically futile treatment. In this way, while giving a medical definition of the condition of brain death, the committee also redefined human death itself (cf. Gervais 1986).

> Our primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is the need for a definition: (1) improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continued to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds occupied by these comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.
>
> (Ad Hoc Committee of Harvard Medical School 1968: 85)

Following the report of the Ad Hoc Committee, brain death was taken as a new indicator of human death, alternative but equivalent to cardio-circulatory arrest, in the legal jurisdictions and/or clinical protocols of the majority of countries (Wijdicks 2011), ratifying the position of the WHO which states that:

> [Brain death is the] irreversible cessation of cerebral and brain stem function; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. *A brain dead person is dead*, although his or her cardiopulmonary functioning may be artificially maintained for some time.
>
> (WHO, emphasis added).[16]

[16] From the WHO Global glossary of terms and definitions on donation and transplantation 2009: http://www.who.int/transplantation/activities/GlobalGlossaryonDonationTransplantation.pdf

# The Brain Death 'Problem' in Japan

In Japan, brain death became one of the most widely discussed and controversial issues of bioethics. In 1968, the infamous Wada case focussed the attention of the Japanese public on the delicate ethical questions raised by the emergent enterprise of organ transplantation. As discussed in the introduction, the death of the young recipient Miyazaki-kun in as little as eighty-three days after the operation prompted an investigation into Dr. Wada's conduct and made the circumstances of the case the centre of intense public scrutiny. Dr. Wada was charged with double murder, accused of having killed the 'donor' and procuring his organ without the family's consent, as well as having caused the death of the recipient whose condition allegedly didn't require such an invasive and unsafe intervention (Lock 2002). Disturbing evidence emerged suggesting that the case had been a "barbarous piece of medical experimentation" (Lock 2002: 133), but the truth is that the tragic outcome of the Wada transplant was typical, as had been, in many respects, the management of the donor and the recipient.

At its inception, and for some time after, organ transplantation in general and cardiac transplantation in particular were experimental, rather than therapeutic, treatments (Fox and Swazey 1978). Survival times were a measured in days, weeks or, at best months. They were more akin to palliative care than contemporary transplantation outcomes. Driving the enterprise of transplantation, in the face of such dreadful clinical results, was what Fox and Swazey famously called "the courage to fail" (*ibid*). In the absence of ethical and professional guidelines, surgeons acted as gatekeepers of clinical research. They selected recipients, approved of living-related donations, operated on donors who had died at the same medical facility and whose family's consent they obtained themselves, as systems of organ sharing didn't yet exist, and they did so guided by a professional ethos that praised risk-taking and recourse to extreme measures in the attempt to save patients at immediate risk to life (*ibid*). While the judgment remains open on Dr. Wada's intentions and

conduct, what is generally agreed is that the first heart transplants would not have been possible under current ethical guidelines.

In fact, after 1986 was named the year of heart, the years that followed saw the number of operations drastically dropping and cardiac transplantation effectively entered a phase of clinical moratorium (Fox and Swazey 1978). Questions began to be asked, both by experts and the general public. Is such a resource-intensive and clinically unsafe treatment even worth researching? Who should regulate the selection of recipients (and how), were the procedure to become routinised? Is it ethically acceptable to redefine death for transplantation purposes? Is it even possible to define when death truly happens, and who has the right to do so?[17]

Such questions were not at all unique to Japan. While in other countries the polemic gradually settled down to become a matter of technical judgment for experts, in Japan the brain death 'problem' developed into a sort of “national obsession” (Feldman 2000: 51). The debate encompassed patients’ organisations, political, medical and religious institutions, and generated thousands of newspaper articles, books and television programmes by public commentators and scholars, as well as periodic polls to survey national opinion over the vexed question: is brain death human death (*nōshi ha hito no shi ka*)?

*From Clinical Judgment to Social Problem*

Over the years, medical associations, university ethics committees and ad hoc advisory bodies appointed by the Ministry of Health Labour and Welfare (MHLW) took up the task of defining diagnostic standards. In 1985, the Brain Death Study Group set up by the MHLW issued an official protocol for the determination of brain death named after Takeuchi Kazuo, the neurologist, who chaired the committee, the Takeuchi Code (*Takeuchi kijun*) (Feldman 2000; Lock 2002). It adopted a conceptual definition of whole brain death as the

[17] For an example of how similar questions were raised in the media see the editorial of the Saturday Evening Post (1968), titled ‘Frankenstein in South Africa’. See Fox and Swazey (1978) for a detailed discussion on the debate among medical professionals leading to the moratorium on cardiac transplantation.

"irreversible loss of brain function in the entire brain, including in the brain stem" and prescribes a set of various clinical tests[18], to be performed twice over a minimum six-hour interval. Still in use today, the Takeuchi Code is in line with internationally endorsed diagnostic standards refined over years of clinical observation, and, if anything, it can be considered a particularly conservative convention. The tests it prescribes have been largely reviewed in the medical literature and unanimously considered sensible and reliable diagnostic tools, when correctly applied (Wijdicks 2011; Pallis 1996). Clinical data are adamantly clear that a sound diagnosis is a sufficient and conservative criterion by which to exclude any possibility of recovery and to anticipate cardiocirculatory arrest. The Japanese Association of Acute Medicine (JAAM) thus officially endorsed the adoption of the brain death criterion. The approval of diagnostic standards, however, did not put an end to the dispute.

The controversy over the redefinition of death was particularly rife among Japanese civil society. In the 1960s and 1970s, alongside the rise of social movements for the promotion of civil rights in Japan, patients' rights (*kanja no kenri*), marked the appearance of bioethics (*seimei rinri*) discourses and reasoning as a field of specialisation (Feldman 2000). In a country with a highly specialised and relatively equitable health-care system[19], the crucial issues at stake in discussing health rights concerned the ethics of clinical practice. Under the labels of informed consent and patient's autonomy, grass-roots groups denounced the authoritarian and paternalistic nature of the doctor-patient relationship and the excessive degree of control granted to medical professionals over patients and their families with regards to information disclosure and therapeutic choice (Feldman 2000).

Patients' groups and grass-roots associations in support of the rights of the mentally ill, the disabled, and victims of traffic accidents vehemently opposed the redefinition of death by neurological criteria as a new form of

[18] See Chapter 6.

[19] Japan has universal health coverage and an advanced healthcare system providing high quality basic and specialised care (for more see Chapter 4). From its effective costs-management, to its achievements in terms of scientific research and the population's general health (Japan has one of the highest life expectancies in the world), the national medical system has attracted the interest of foreign policy-makers and researchers. For an overview of these issues see the special issue of the Lancet on the Japanese healthcare system (Reich et al. 2011).

eugenics (Feldman 2000; Lock 2002; Yamaguchi 2011). Their opposition to brain death powerfully called upon Japan's past history of medical atrocities and health-related discrimination, from modern eugenic politics, to the infamous human experiments of Unit 731 during WWII[20]. What is more, it worryingly evoked contemporary public health tragedies, such as the infamous HIV blood-tainted scandal (Kingston 2004). In the wake of the polemics around the Wada case and following episodes of malpractice in organ procurement and transplants, the stance taken by the social movements in defence of disabled patients brought to the fore terminal patients' right to self-determination, which in other contexts was largely glossed over by the arguments for the withdrawal of treatment as a form of "death with dignity".

Backing-up their position, the Japanese Bar Association repeatedly issued statements against brain death, warning that a statutory redefinition of death as brain death in order to authorise lawful organ procurement would have run contrary to terminally ill patients', and their relatives', rights to care (Feldman 2000).

By highlighting the legal controversies of the matter, the intervention of legal scholars and professionals underlined how the solution to the question of whether brain death was human death could not simply ratify the opinion of medical experts. As the role of the law acquired an increased relevance in the debate, professional politics also split on the brain death problem. Differently to North America and Europe, where opposition to the legalisation of treatment withdrawal for terminally ill patients came mostly from conservative parties close to religious institutions, in Japan both left wing and radical politicians firmly campaigned against the recognition of brain death. Siding with the advocates of disabled and terminally ill patients, the Japanese Communist Party and eminent members of the Social Democratic Party firmly opposed the passing of legislation in favour of brain death (Nakayama 2010). They formed a powerful interest group that, while giving voice to the claims of patients' groups, also asserted the political influence of medical and other professional organisations, such as the Bar Association and the Japanese Paediatric Association, both of

[20] See for example Frühstück (2003) and Robertson (2002) on modern eugenics; Nie (2010) on war crimes and medical abuses; Kingston (2004).

which traditionally opposed brain death.

Effectively cast as an issue of interest and concern for society at large, the brain death problem became a favourite in Japanese public and scholarly debates. While selected sources are used throughout the thesis when relevant, to review the large amount of literature in the Japanese language on the problem is beyond the scope of this discussion. What should be stressed, however, is the impact that the discussion had in fuelling the public debate and imagination. Lock describes how articles, popular and fictional literature, as well as TV programs on brain death proliferated throughout the 1980s-90s, which alongside repeated surveys effectively kept the issue firmly at the centre of the public debate (Lock 2002). Cultural commentator Yanagida Kunio, son of one of the most famous Japanese historians, tackled the issues in a book and TV specials on the story of his son who had become brain dead (Lock 2002). Scholars also publicly intervened in the debate. Morioka Masahiro, philosopher and author of a hugely popular book on the topic and notoriously critical of brain death, was frequently interviewed in the media, even on the occasion of the recent reform of the Act on Organ Transplants in 2009. Anthropologist Namihira's (1988) argument that the Japanese do not regard the dead body as a mere thing, as indicated by the fact that people talk of the body of a deceased in honorific terms (*itai*) and consider the generic term corpse (*shitai*) disrespectful (cf. Lock 2002: 215), became common knowledge, and during my fieldwork both interlocutors and people completely unrelated to transplantation drew upon this point to explain to me the local uneasiness with organ transplantation. Maybe one of the best-selling and most influential books on the topic was *Brain Death* a detailed investigation by journalist Tachibana into the logic of brain death as a diagnostic concept that in many ways can be considered to anticipate the recent debate among North American and European neurological experts on the medical flaws of the brain death concept (1986).

What, then, contributed to the wide social interest and concerns around brain death in Japan? What actually happened in and around Japanese ICUs?

*Death in Japan*

In her compelling analysis of the brain death problem in Japan, Lock argues that ancestors were the unspoken presence behind many of the arguments opposing brain death (2002). Ancestor worship in Japan is a socioreligious set of practices strictly related to the continuation of the household (*ie*) system, and maybe because of this central role in reproducing social life through mortuary rituals, it has come to epitomise more general images and practices surrounding death. Lock maintains that people in contemporary Japan engage in the funerary and memorial services in a much more varied and less formal way than in the past, but she still believes that the spirits of the decreased, as well as the practices through which people engage with and care for them, continue to profoundly shape the "eternal engagements" between the living and the dead that ancestor worship exemplifies (Lock 2002; Smith 1974).

Traditional mortuary practices in Japan construe the passage to the afterworld as an extended process. When a person lies dying, family members and people at her bedside perform a ritual of attempted resuscitation (*sosho*, or *sosei*) to bring back the spirit (*tamashii*) that leaves the body as the person stops breathing (Suzuki 2000). A doctor is then called to determine death, and the family contact the Buddhist temple for a priest to be sent to perform the recitation of sutras (*ibid.*). The wake on the night of the death (*tsuya*), the funeral ceremony and the burial, all involve the participation of the community at large (*ibid.*). The body is prepared at home, and laid with the head facing north, after being dressed in a white kimono folded right over left (as opposed to left over right which is for the living). The coffin is carried out of the house through a window and brought in procession to the graveyard. Upon returning, people wash their hands and sprinkle salt over their clothes and on the streets to purify them. The rituals symbolically revert to the order of everyday life to mark the separation of the deceased from the world of the living and therefore protect the latter from the impurity (*kegare*) associated with death (Suzuki 1974; Raveri 1984).

The funeral ceremony is followed by a mourning period that can last from thirty-three to fifty days and is punctuated by periodical memorial services.

These are scheduled to symbolically mirror the rituals of coming of age and maturity, and as life-course rituals configure the integration of the living into the community, so the memorial services mark the process of uniting the dead with the ancestral lineage in the afterlife (Smith 1974). Once the spirit leaves the body it sets out on a journey towards becoming a Buddha (*jōbutsu*) that doesn't depend on the person's conduct during life but rather on the appropriate engagement of the bereaved family in the rituals of death (*ibid.*). The process of becoming a Buddha is one extended in time and that is at risk of failing until it is completed, potentially leaving the spirit wandering restlessly and returning to haunt the living. Through mourning rituals, the bereaved accompany the spirit of the dead and make sure it is safely united with the ancestors that protected the household.

Along with the formalised services, people engage in various practices to memorialise and care for the spirits of the deceased. New Year's Eve, which represents an occasion for scattered families to gather together, is also a time of remembrance of the dead, as it is O-Bon, one of the major annual festivals in Japan when the spirits are collectively memorialised (Smith 1974; Steffánson 1995). People also engage with the dead in a more intimate way. When visiting the grave of a family member, for example, people don't simply pray to/for the deceased, they bring personal objects as well as food and drink that they occasionally share with the dead as they talk to them about their and their family's life. It is also common practice to keep a domestic altar (*butsudan*) where offerings of food and incense are made to pictures of the dead. In contemporary Japan, death practices, ranging from contemporary funerary ceremonies to burial and memorialisation practices, are increasingly configured around the remembrance of the individual person rather than the worship of household's ancestors (Suzuki, H. 2000; Suzuki, I. 2011; Smith 1999). Drawing on new repertoires and influences, people continue to memorialise and care for the dead and to cultivate enduring bonds of mutual solidarity with them.

Lock argues that it was this local sensibility towards death as a social event that underscored the critique of brain death in Japan. Death being social is hardly unique to Japan: in every human society, imageries of the afterlife and mortuary practices shape local cosmologies and the place the dead inhabit

within them. In Japan, this means that the social obligations towards a dead family member contribute to the depiction of organ procurement as disrespectful and morally problematic –as the famous novelist Endo Shusaku, put it, it was "an insult to the dead" (*New York Times 1987*). From this perspective, the Japanese critique shed important light on the historically and culturally contingent assumptions underscoring the redefinition of death. First of all, it highlighted the problem of conflating the "process of becoming dead" to a single moment in time (Lock 1996). Further, it revealed how the concept of brain death rested as much on an accurate knowledge of human physiology as on the implicit premise that social and cultural notions of death are nothing but mere superstructure to such objective knowledge.

*The Body: or, What Biological Is It Anyway?*

Rituals of death also serve, as mentioned, to protect and purify the living from the impurity (*kegare*) of death. In Shinto, *kegare* is a taboo condition deriving from naturally occurring phenomena, such as death, disease and dirt. *Kegare* possess a polluting quality, it adheres to the person and contaminates the surroundings, bringing misfortune and social disruption.[21] Handling or coming in contact with it must therefore be avoided and/or followed by purification. *Kegare* thus functions as a moral concept in drawing and maintaining boundaries that are often inscribed on the body (Raveri 1984). The dead body is a source of *kegare*, and so are bodily substances such as blood, body fluids and excrements. Purity, it appears, is maintained through the integrity of body boundaries. Using the dead body and cutting into it is abominable, a reason that is also associated with the low rate of autopsy in Japan. The concept of *kegare* draws attention to the way in which the body is a key classificatory device within local cosmologies and moral orders; it is not just inert flesh, but is mapped, used and indeed embodied in culturally and socially specific ways.

As Lock argues, while biomedical knowledge is the dominant medical tradition in contemporary Japan, concepts of the body deriving from Chinese medicine make intuitive sense to people and appear to inform body practices

[21] See Suzuki (2000) on *kegare* in relation to the preparation of the body for the rituals of death.

(Lock 2002: 226). *Ki* is a physiologically oriented concept indicating a vital force diffused throughout the body and is pervasively drawn upon to express physical wellbeing and energy (cf. Ohnuki-Tierny 1984). Along with *ki*, *kokoro* (heart) also refers to an essence dispersed through the body which is not biologically oriented. Like the English equivalent, *kokoro* is associated with emotions, feelings and one's inner self; it is not biologically located in one organ (the heart in an anatomical sense is *shinzo*) but neither indicates abstract consciousness; instead, it points to an idea of incarnate mindfulness (cf. Scheper-Hughes and Lock 1987).

These concepts of the body radically depart from those underlying brain death. The concept of brain death maintains that human death can be surmised from the loss of function of one single organ, the brain. This position, as Gervais pointed out in her critique of brain death, radically departs from previous notions of human death, as the traditional criteria of cardiac arrest identifies the end of life not with the ending of cardiac activity but with the cessation of vital signs in the entire body that is consequent upon it (1986). The rationale of giving primacy to the brain as the single organ whose failure is equivalent to death even though the rest of the body retains vital functions rests on two distinctive arguments. Firstly, the brain is taken as the locus of consciousness, its irreversible decay marks the end of what can be considered human life as opposed to mere biological existence (Aagamben 1998). Secondly, the loss of cerebral function is considered the point of no return in the irreversible process encompassing the cessation of animation and the beginning of the body's decomposition which constitutes death from an organic perspective by reason of taking the brain as the "critical system" that superintends and organises the life of the organism as an integrated whole (Bernat 1998; cf. Shewmon 1998, 2001). While radically different from, and to some logically inconsistent with, one another, both these positions maintain a dichotomous view of the brain and the body.

Local notions of the body in Japan complicate this simplistic view, as they conceptualise both cognition and organic integration in terms of a unity of the body and the mind. Opponents of brain death in Japan therefore explicitly contest the neurological criterion for death being a tacit reification of the ethno-

centric model of Cartesian dualism (Lock 2002). Given this perspective, the debate in Japan anticipated the emergence, starting from the 1990s, of renewed interest and controversy around brain death in North America and Europe. This re-examination of brain death, which produced endless arguments and counter-arguments among medical, legal and bioethical experts and even prompted a second U.S. President's Council on Bioethics, highlighted the logical and physiological inconsistencies between definition, criteria and tests for brain death as constituting the concept of human death. The conundrum of whether brain death is human death, which in North America resulted in a convoluted back and forth among a few experts, was made public in Japan. The debate thus pointed out how the problem was not prognostic but epistemological, the question being not what science knows but how it knows it (Lock 2002).

*Personhood: or, Who Are Your Others?*

The critique of the arbitrariness of the concept of brain death often took the form of a cultural opposition between Japan and the West. Brain death was associated with foreign modernity and depicted as a threat to core cultural values, mobilising a century-long reflection on the relationship between "Western technology and the Japanese spirit" (*wakon yosai*).[22] As Lock (2002) illustrates, one of the most pervasive arguments against the new death was to reject the technological intrusion into the 'natural' process of death (cf. Long 2001). Nature (*shizen*) is conceived here as that which is without artifice, a realm of causal necessity that isn't limited to what lies outside human society but points to the unity between the self and the world (Martinez 2005; Berque 1997). This ideal of nature is most powerfully represented in the construction of the landscape, in which the meticulous human labour of manipulation of the environment is ultimately aimed at concealing itself to reproduce the image of an unrefined naturalness. These socially constructed images of nature, which in fact are not natural at all, emphasise living in harmony with the world as,

[22] See Lock (2002: 44) on how these arguments were drawn upon in the debate over brain death in Japan.

supposedly, a distinctive characteristic of Japanese traditional culture and opposed to the drive of Western civilisation at controlling and using nature to man's advantage. *Shizen* thus functioned as a powerful moral touchstone against the technological manipulation of death (Lock 1997). As Lock rightly observes, however, not all technological manipulations of nature are the same; some, like abortion or prenatal testing are morally unproblematic, even enhancing of nature (Lock 2002, 2001; cf. Norgren 2001). The mobilisation of nature as a moral arbitrator against brain death expressed wider social anxieties, which are hardly unique to Japan.

Long shows that death in hospital is as "unnatural" to Americans as it is to the Japanese (Long 2001). In both countries, a "good death is that which happens surrounded by family in a familiar environment ("laying on the tatami" as the Japanese say), and which doesn't impose any burden on others or cause pain to the person (Long 2003). While these concerns are largely trans-cultural, the ways in which good death is reconfigured in practice are context-specific, and in an era in which more and more deaths happen in a medical setting, the 'naturalness' of death comes in fact from the technological manipulation of its timing, cause, and modalities (Long 2001; cf. Kaufman 2006). Long illustrates that, while Americans dread the indefinite 'lingering' in between, and put emphasis on choice, for the Japanese the most feared prospect is dying in a hospital bed while the family waits in the hallway (2002: 66). If, for Americans, the natural way of dying is one free of artificial intervention, for the Japanese natural death is the end of a natural life. Emphasis isn't put on the distinction between the human form other forms of life but rather on the participation and involvement of significant others (*ibid.*).

Long's argument comes with a warning against overdrawing these differences, yet it provides rich insight into how to understand the cultural construction of natural death. In particular, it shines a light on how different notions of personhood and relatedness inform the processes of dying. Adhering to local conceptions of the body are specific notions of personhood. While arguably the self is socially constructed everywhere, in Japan, particular emphasis is put on how the self comes to be negotiated through the networks of social relationships the person is embedded in, rather than on the ideal of the

self as being synonymous with intimate and individual identity (Kondo 1990). What makes a body into a person, therefore, is neither consciousness nor the persistence of animation alone, but the moral investments that significant others have in that body. As Morioka (1989) famously argues, “brain dead bodies” are in fact “brain dead persons” made of networks of social relationships.

This emphasis on relational personhood means that what a person does with their body is not exclusively the decision of the individual, but the person’s significant others are supposed to have a say in medical decisions (Lock 2000; cf. Kato and Sleeboom-Faulkner 2011*b*). As Lock (2002) notes, this cultural sensibility doesn’t exclude arguments of a different sort; if anything, it resonates and reinforces wider social concerns. The sociologist Nudeshima (1991), for example, argues that the opposition to brain death in relation to transplant in Japan was largely influenced by the paternalistic and authoritative character of medical practice and policy-making in the country, both of which lack appropriate mechanisms for promoting informed and participatory decisions. Against this background, as seen, patient-activists and legal experts underlined the risk that leaving the determination of “the invisible death” (Nakajima 1985) to physicians alone could open the way to medical abuse and conflicts of interest over organ procurement. A similar worry underscored the concern that families might feel obliged to consent to donation out of a sense of indebtedness towards the physician, highlighting the primacy of the family’s obligations towards the deceased over ideals of solidarity towards strangers (Lock 2002). Interestingly enough, the 2009 reform of the policy on organ donation in Japan reinstated this notion of the collective ownership of the body by introducing the clause of so-called “preferred donation” (*yūsen teikyō*), which allows those who register as organ donors to indicate the will that, in case of their death, organs are allocated to a family member who is on the lists for a transplant.

As it casts a light on the moral obligations at stake in decisions over the body, the Japanese critique of brain death greatly complicated the notion of the end of human life as a loss of brain function. From this perspective, to argue that brain death stripped death away from the web of social relationships that constitute the person would be to miss the point entirely. What the brain death

problem shows is that any definition of what counts as death, and therefore of what it means to be human, is also a negotiation of the moral and political worlds that the body is part of. The question then is, in what social networks and political economies of death the body became entangled through the development of organ transplantation.

## Creating Demands, Seeking Supplies

In 1971, one of the preparations screened at the laboratories of Sandoz, a subsidiary of multinational drug company Novratis, was found to have strong immunosuppressant properties. Transplantation was still largely experimental, many centres had put a halt to cardiac transplant, and the lack of a market for immunosuppressants didn't justify significant investment by Sandoz (Stahelin 1996). It was a causal experiment that gave researchers the cue (swapping water with oil as a solvent) to synthesise a drug from the compound, derived from a Norwegian fungus and named cyclosporine. Clinical trials, and in 1983 the commercialisation of cyclosporine, inaugurated a new generation of immunosuppressant drugs. This opened the way to a new era in transplantation medicine, one characterised by the effective mobilisation of flesh (Cohen 2005).

Efficacious immunosuppression didn't only enable the control of rejection in recipients, it also widened the pool of potential donors by rendering a perfect tissue match unnecessary. As the anthropologist Cohen (2003: 685) illustrates, it dramatically transformed the notion of operability in transplantation, meaning "the extent to which a person's body is available to be incorporated into something or someone else given the relation between techniques (here, surgical and pharmaceutical techniques) and market structures". Cohen (2001: 21) argues that contrary to what Haraway describes as a shift from the organic life to code, immunosuppression reconfigured the logic of transplantation from one based on the recognition of biological difference to an exchange in substances where the code is technologically bracketed and body parts are made homogeneous and interchangeable with each other. Organs were made

detachable not only from bodies but also from persons, and with the concomitant development of globalisation, they entered new circuits of exchange, largely unregulated and shaped by profound inequalities.

The phenomenon of organ trafficking and transplant tourism has emerged as a new dimension of transplantation medicine and has developed globally. A growing number of affluent patients have resorted to the black market to access scarcely available and life-saving resources. Easily reachable through the internet, brokers offer patients from well-off countries package tours, with comprehensive medical and travel expenses, including to China, India, Bangladesh and South-East Asia (Scheper-Hughes 2000, 2001, 2005; Cohen 2001, 2003, 2005; Moniruzzaman 2012). At other times, they arrange for the journey of prospective recipients and recruited organ sellers to complicit clinics in third countries (Scheper-Hughes 2000, 2001). Transplant surgeons too are personally involved in international trafficking and domestic cases exist of bribery in which they have authorised living donation from unrelated 'donors' (*ibid.*).

Japan is rumoured to be heavily involved in the phenomenon (Fujita, Slingsby and Akabayashi 2010; New York Times 2009a; Matsuno 1998), and is listed among the major "organ importing countries in the world" (Shimazono 2007). The phenomenon, known in Japanese as *kaigai tokō ishoku*, or simply *tokō ishoku* (literally, 'transplants overseas') covers a range of very different practices (cf. Yamazaki 2007). Travel for transplantation purposes to North America, Europe and Australia, has become increasingly common since the early 1990s, and although the data are scattered, the number of reported cases is in the hundreds for heart transplants alone.[23] Usually sponsored through public fundraising, these instances of *tokō ishoku* are commonly arranged between Japanese hospitals and overseas clinics relying on policies enforced by national organ sharing networks that regulate the allocation of organs to foreign patients (see Chapters 2 and 4). Alongside this practice, instances of proper transplant commercialism also exist, particularly between neighbouring Asian countries such as the Philippines and China.

For obvious reasons, the extent of the phenomena are difficult to grasp,

[23] See Tomomatsu (2013).

and different forms of international mobility for transplant purposes hardly match neatly defined ethical guidelines, as they often blur the lines between illegal and extra-legal practices, exploitation and humanitarianism, body commodification and altruistic gifts (Cohen 2005). What is generally agreed is that the phenomenon has been constantly on the rise over the last decades, as a result of improvements in clinical management of transplants, the growing convenience of international travel and communication, and the spread of technology to countries such as India and China that specialise in the accepting of foreign patients (Nullis-Kapp 2004).

These phenomena have emerged as the most controversial and visible arena of debate concerning the ethics of transplantation, especially after international organisations took an official stance on the problem. In 2008, the International Transplant Society issued the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, condemning the phenomenon of 'transplant commercialism', and the following year the WHO endorsed this position by encouraging the passing of favourable legislation to grant patients access to care at a local level. Through these moves, organ trafficking and transplant tourism, so far poorly known and even dismissed as urban legends, became the centre of mounting public and professional concern. The procurement of organs from executed prisoners in China, and the black market in kidneys from impoverished sellers, often coerced into exchanging an organ for money and left with no medical assistance after the operation, have raised troubling questions concerning the human rights of the 'donors'.

Against the background of the spread of organ trafficking, the debate is rife in bioethics and related disciplines about what role, if any, the market can be granted in the regulation of organ transplants, and proposals that only a few decades ago would have been radical have fully entered the public arena. For some, the fact that an organ market is already a reality is symptomatic of the urgent need for regulation, rather than prohibition. Proponents of legalised organ selling, as is authorised in Iran, maintain that this would be the safest way to protect the rights of destitute people who are ready to give away a part of their body for money, while it would also positively improve the availability of life-saving organs for the many patients in need of these therapeutic resources

(Radcliff-Richards et al. 1998). Without going so far, the possibility of financial incentives for organ donation, in the form of funeral expenses, medical insurance, or other compensation, is regarded as a viable and potentially useful strategy to encourage people to sign up as organ donors[24]. On the other hand, horror at the commodification of the body is rooted in a fundamental critique of contemporary capitalist society, so that the prospect of a legalised trade in human bodies is perceived as dreadful by most for it brings to mind "a literal market in the very things that Marx used as metaphors of capitalist excess" (Healy 2006: 5). The line of reasoning famously proposed by Titmuss (1970), according to which a regime of free donation fosters social solidarity and is therefore the fairest and most efficient model of organising exchanges in body products, continues to remain firm in both the specialist and popular discourse, although with the increased systematisation and spread of organ procurement, his argument on the altruistic gift appears increasingly to be an essentialised rather than an empirical description of the actual processes through which body parts are procured, processed and distributed (Healy 2006; Waldby and Mitchell 2006; Yamazaki 2011a, 2011b).

If Titmuss' argument on the altruistic gift has been one of social sciences' most successful contributions to the public discourse, anthropologists' analyses of transplant tourism and traffic have been no less influential. Scheper-Hughes, who most famously called attention to the practice of organ buying and selling and collaborated on the drafting of the Declaration of Istanbul, has been amongst the most outspoken critics of the logic of body commodification that, as she sees it, underscores contemporary transplantation (2005). Scheper-Hughes maintains that if the majority of arguments advanced in the debate on organ transplants draw the line between market relations and free gifts, from an anthropological point of view the problem arises when a person identifies in another human being a body as a resource for potentially life-saving recourses (2005: 161). The development of transplantation, she thus argues, has brought about new "medically 'incited' tastes for human bodies, living and dead, for the

[24] Similar proposals are considered, for example, in the report by Nuffield Council on Bioethics (2011) 'Human bodies: donation for medicine and research' by a team of experts including anthropologist Merylin Strathern. The report concluded that financial incentives, such as the payment of funeral expenses by the NHS, coud be viable strategies to tackle the current shortage of organs for transplants in the UK.

skin and bones, flesh and blood, tissues, marrow and genetic material of the 'other'" (Shceper Hughes 2001: 54). This, in turn, has reconfigured the very relationship with the 'other'. What Scheper-Hughes calls the "fetishisation of life" itself (Scheper Hughes 2000: 2011) narrows down the bioethical focus from the consideration of the dignity of the body as a person to a concern on how best to procure body parts.

Hamdy (2012), on the other hand, illustrates through her ethnography of transplants in Egypt, that once body parts are effectively circulated as desirable things, ethical reasoning can only leave room for the question of what principles we can afford, against the complexity of the socio-economic forces and human relationships. What is more, these are never defined as fixed categories, as Cohen (2005) beautifully illustrates in his ethnography of organ selling in India. On the one hand, Cohen argues that the suppression of biological differences by means of anti-rejection drugs marks the shift from human life to bare life not just by making organs into comparable objects, but in the original sense of Agamben's bare life as that in which death is not recognised as a sacrifice (*ibid.*). It is this logic, Cohen argues, that underscores the preference for compensated sellers over the possibility of putting a loved one at risk through living-related donation (*ibid.*). On the other hand, the act of selling a kidney is tangled up in a political economy of love in which giving up on a part of oneself to financially contribute to the wellbeing of one's family becomes a way to reappropriate one's role as a social persona in conditions of extreme marginality (*ibid.*).

These ethnographies show how, even when commodified and reduced to bare life, the body is never just a thing (cf. Schepher Hughes 2005). It always sits at the nexus of economic forces, and moral obligations and social relationships that biotechnological intervention doesn't stand in opposition to, but rather becomes entangled with. It is no surprise that this powerful anthropological critique stems from an analysis of the organ market, for this is an arena where the reconfiguration of life in relation to transplantation is brought into question in particularly problematic ways. However, it is not the only one.

# A Camel Through the Eye of a Needle

In 1997, the Japanese Diet passed the Act on Organ Transplants (*zōki ishoku ni kansuru hōritsu*) that legalised organ procurement from the brain dead. The law came about as a way out of the impasse in which transplantation medicine had been caught for almost thirty years since the Wada scandal. As the country was grappling with the brain death problem, the development of transplantation medicine worldwide made it increasingly compelling to authorise organ donation in order to make available this life-saving treatment within the national health-care system. The question was how to authorise the lawful procurement of organs from brain dead patients without giving a statutory definition of death that would equate it with such a contested diagnosis.

The Japanese law stipulated that the diagnosis of brain death was to be taken as equivalent to human death only in cases of organ donation. The national policy on organ donation and transplants, therefore, set up a so-called system of opting in, under which only patients who have explicitly given consent for their organs to be procured are eligible as donors.[25] Different from the equivalent international policies however, the Japanese law prescribed that patient's written consent was mandatory not only to authorise organ donation, but also to pronounce the person deceased on the basis of a diagnosis of brain death. In this way, upon signing a donor card, patients were given the option of choosing their own definition of death, and deciding whether to be taken off artificial life support after the neurological diagnosis or following cardiac arrest (see Lock 2002: 185-190). Furthermore, the family was given the right to overturn the patient's decision. Under this particularly strict policy, organ donation from brain dead patients continued to remain very rare. What is more, because the donor card assumed a legal value to determine the person's will concerning end-of-life care, patients younger than fifteen were automatically ruled out as potential donors because they were under the age limit to express

[25] The opposite system of so-called presumed consent, or opt-out, stipulates instead that all patients who meet the clinical standard of brain death are potential donors, and family consent is sufficient for organ donation. After the reform of the law on transplants in 2009, organ donation in Japan is currently regulated according to an opt-out system of consent (see Chapter 5)

valid legal consent. As a consequence of this clause, paediatric transplantation, particularly heart transplantation that can be carried out only from brain dead donors, became virtually impracticable, as organs procured from adult patients cannot be transplanted into children under a certain body weight.

While in this respect, the Japanese case is singular, scarcity is hardly a problem peculiar to Japan. The perfected therapeutic efficacy and increased availability of organs consequent upon developments in immunosuppression have made them into scarce goods (Koch 2001). The commercialisation of cyclosporine brought a phase of unprecedented expansion of transplantation. Even though in the public discourse, organ transplantation is still commonly depicted as a miracle, it is one routinely happening. Approximately 100,900 transplants are performed worldwide each year (GODT 2010), not including those carried out clandestinely. While it arguably remains a resource-intense and clinically uncertain option, transplantation is nowadays commonly on offer and amply invested in, at least within healthcare systems oriented towards high-end technologies. These developments, together with the creation of specialised agencies and international cooperation schemes, have resulted in an expansion of waiting lists, including new pathologies treatable with a transplant and relaxing the criteria for patients' eligibility (see Scheper-Hughes 2005). Between 1988 and 1991, for example, the number of patients on the waiting list in the U.S.A. grew by 55%, while donations only increased by 16% (Arnold and Youngner 1993). The 'supply', it seems, has never been able to meet the 'demand', and scarcity has emerged as the dominating framework in which transplant medicine operates. Organs, it seems, became scarce when they became available, routinely and effectively procurable.

Scarcity has thus emerged as a new problem that this field of medicine is confronted with, and as the dominant framework of debate within which practically every aspect of organ transplantation has been discussed. Alongside the already mentioned debate over the effects of the regime of donation *vs.* possible financial incentives on the shortage of organs, clinical practice has emerged as the other relevant site of discussion. Much less visible in the public arena than the sensational phenomenon of organ trafficking, the legal procurement of organs is equally, if not more, controversial. Schemes to

promote efficiency in organs procurement, such as the Donor Action Programme adopted in Spain, are among the strategies to tackle organ scarcity in practice. The prompt identification of potential donors, the effective request of consent from the family and clinical protocols especially devised to preserve organ functions have guiding principles that transplant coordinators are trained in and try to implement on the ground. Without going to the lengths of introducing the buying and selling of organs, some argue, the systematisation of organ procurement, distribution, and allocation has brought about a shift from the cure of the person to the focus on body parts, and already requires and involves taking "distinct, particular, incommensurable gifts and processing them into general, homogeneous, comparable items" (Healy 2010: 123; Fox and Swazey 1992; cf. Hogle 1995).

At the same time, the definition of death again became a matter of debate. In 1993 the Pittsburgh protocol approved non-heart beating donation from patients who had died of cardiopulmonary arrest in a medically controlled way. Departing from the traditional procedure for kidney and cornea procurement from non-heart beating patients, the new protocol required the withdrawal or withholding of life-support treatment in the function of organ donation. By reducing the time between the moment when the patient is weaned off ventilation and the retrieval of organs, and by intervening to pre-treat the donor while he/she is still alive (Lock 200), the protocol enables the procurement of organs, including the heart, from non-heart beating patients at a time when they are still viable for transplantation purposes. Bioethicists and social scientists engaged in the debate on transplantation severely criticised the practice, and Fox (1993) even called it an "ignoble form of cannibalism". As they pointed out, the Pittsburgh protocol, and those that followed, authorise organ retrieval at a moment when death is still technically reversible and is determined only by the decision not to resuscitate. In this way, the ethical principle that the patient must be dead at the time of donation is subtly reverted, legitimising the possibility of letting the person die for the sake of procuring organs (Arnold and Younger 1993).[26]

[26] The practice is not in use in Japan. Unless differently specified, therefore, any mention of non-heart-beating donation in the context of Japan must be intended as referring to the

While NHBD raised new polemics, the redefinition of death as brain death, which was largely considered a settled question in bioethics, again became a matter of controversy. Improved ICU care made it possible to sustain brain dead bodies for longer times, while at the same time, further research into the physiology of brain death, which ironically enough was aimed at perfecting organ preservation, showed that patients who met the clinical standard of brain death, in fact retained some brain function. On the basis of these clinical findings, Halevy and Brodey (1993) famously contested the redefinition of death as brain death, pointing to the logical inconsistency between the underling concept of death (that the brain is the integrative centre of the organism and its death can therefore be equated with point of no return of organic death), the standard of whole brain death (that defines it as the loss of *all* brain functions), and clinical tests to determine the condition. Neurologist and paediatrician Shewomon, one of the most vociferous detractors of the concept of brain death, made a similar critique. Reviewing data from a number of brain dead patients maintained on artificial ventilation, including cases form Japan, he famously contested the self-fulfilling character of the diagnosis of brain death (Shewomon 1998*a*). While the prognosis of imminent cardiac arrest was built into the foundation of the definition of death as human death, Shewomon indicated that one of the patients had met this criterion, but, when treatment was continued, some had survived for up to one year or more (*ibid.*). Shewomon went a step further in his critique, and argued that the death of the organism that in some cases follows the death of the brain is not necessarily attributable to head trauma but results from the interrelated effects of brain trauma on multiple systems in the body, particularly cardiac function (Shewmon 1998*a*, 1998*b*, 2001).

The reopening of the controversy even caused a transatlantic split over brain death (Widjickis 2012). In America, new clinical findings attesting the persistence of brain activity in brain dead patients promoted a refinement of the concept of 'whole brain death', defined as loss of *all* functions (Bernat 1998; cf.

---

traditional protocol of organ procurement after cardiac arrest. Under this regulation, an interval of several minutes is allowed between the determination of cardiac arrest and the retrieval of organs in order to exclude the possibility that heart functions could be recovered if the patient was reanimated. The practice, therefore, makes it possible to procure only kidneys and corneas.

Halevy and Brodey 1993). The UK, on the other hand, abandoned the concept of 'whole brain death' altogether in favour of the criterion of 'brain stem death', which stipulates that the loss of brain-stem functions alone are sufficient to determine brain death in an anatomically more accurate way (Pallis 1996).[27]

However formulated, the concept of brain death remained confused in practice. Years of clinical experience with protocols for the determination of brain death and organ procurement revealed that even among medical professionals, the new criterion of death was in fact poorly understood on a conceptual level and inconsistently applied in practice (Youngner et al. 1989; Truog 1997). The debate led many to advocate a new redefinition of death, although it was not clear according to which criteria. Some regarded the concept of upper brain death (indicative of the permanent loss of consciousness) to be logically more consistent (Gervais 1986; Veatch 1989), others proposed to return to the traditional criteria of cardio-pulmonary arrest and to abandon the dead donor rule, which prescribed that the patient must be already dead at the time when organs are procured.[28] This, in turn, would have enabled the expansion of the pool of potential donors to include, for example, patients in a persistent vegetative state and terminal patients who consent to treatment withdrawal. In practice, however, concerns remained about the possibility that these changes, which in theory would have expanded the availability of organs, might turn out to have a negative impact on the enterprise of organ procurement, which rests largely on public consensus towards the ideal that organs are donated by the dead.

The rekindling of the debate over brain death revealed how the redefinition of human death on neurological criteria, which had first enabled the mobilisation of 'bare life' in the form of transplantable organs (Agamben 1998), had also come to constrain organ procurement on a large scale. The definition of brain death as human death, which arguably facilitated the public acceptance and professional regulation of organ donation, also enshrined the 'dead donor rule' in legal jurisdictions and ethical guidelines. As it turned out, however, patients

[27] For a detailed overview of the unfolding debate see Youngner et al. (1999).
[28] See Fox (2003) and other contributions to the special issue of the American Journal of Bioethics about the debate over death and the dead donor rule, indicatively titled 'Can We Pause?'

who clinically qualify for organ donation and meet the strict standard of accepted death are not as many as those on the waiting list for organs. Against this background, new strategies to promote efficiency in organ procurement seem caught between the opposite needs of pushing further the limits that constrain donation, while carefully keeping in place the boundaries that define the ethics of the enterprise of organ transplantation.

## Conclusion

Like in the motto of '*ishoku iryō suishin suru'* (developing transplantation medicine), the idea of 'development' in the field of organ transplants is nowadays commonly associated with the effort to move forward in the enterprise of saving lives through this technology and reducing the gap between organ demand and supply. Scarcity is, in this perspective, the problem to solve, the indication that the technology is not working as well as it could.

The historical development of organ transplants, however, reveals how scarcity is built into the way in which the technology has assembled. From this angle, the chapter has shown how organ transplants came together as a heterogeneous assemblage of contingent but unrelated processes neither of which was entirely casual nor casual (Schilch 2010). Underpinning this unstable and contingent assemblage is its strategic function in responding to certain urgencies and needs (cf. Agamben 2009). The clinical success of modern transplants, on the wave of new immunosuppressant drugs and systems for organ sharing, meant that at the very junction when organs became systematically and effectively procurable they were turned into scarce resources in short supply. Commonly seen as the margin of malfunctioning of transplant medicine, scarcity is thus indicative of the rationale that underpins this technology, of the relationships that are at work in stabilising this contingent assemblage.

Cast in this perspective, the case of Japan, the industrialised country with one of the lowest rate of cadaveric organ donation, is not an anomaly but an extreme instantiation of a problem so intrinsic to this technology. Nowadays, scarcity is the dominant framework within which the enterprise of transplantation is conceived and driven. The

rationale of organ sharing management is one that places emphasis on the intense procurement and efficient distribution of recourses, the containment of waste, and the push to near demands that are never fully met. In practice, this means trickle with the definitions of life and death as to push forward the boundaries constraining the pool of potential donors. Yet at the same time, the drive to procure ever more organs also require to safely guard and polish such boundaries in order to avoid breaking the consensus towards the social worth of such enterprise.

At stake in the negotiation of these tensions are questions concerning individual and collective life. Whose lives can be let go of and whose need be saved at any costs? Whose rights need be prioritised? Who partakes in someone else's biological life? And who get to decide? The following chapters analyse how these questions have been dealt with in a context of extreme scarcity as contemporary Japan, and starts with a particularly critical manifestation of such scarcity: the experience of patients who found themselves needing a transplant that was not available in their country.

*TWO*

# *Kaigai Tokō Ishoku*

## *Hope and Uncertainty in Clinical Decisions about Saving Lives*

> Eventually, we're all going to die and lose someone we love. I just happened to experience it earlier than most people.
>
> (Kumano Natsuko)

After discussing the concept of scarcity in the previous chapter, I explore here its most immediate and urgent instantiation: the experience of patients and their families as they seek care and ponder treatment options.

As I have illustrated above, since the late 1980s-early 1990s Japan has seen the emergence of *kaigai tokō ishoku* (travels overseas for transplantation purposes) as a major route though which transplant candidates pursue treatment abroad, either by engaging in organ buying and selling in South East Asian countries or by getting on the lists for the operation in North America and Europe. In this chapter, I take a closer look at one particular form of this phenomenon which has become increasingly popular in Japan: the travels overseas for paediatric transplant.

Frequently reported in Japanese media, the cases of young patients seeking care abroad are relatively unknown outside of Japan. The phenomenon is conspicuous by its absence in social science, with the only exceptions of Yamazaki (2007) and Tomomatsu (2013). Building on their analyses, the discussion below maps the yet largely unknown routes of Japanese patients' mobility, while also contributing fresh anthropological insights on the experience of the people engaging in it.

Through the dilemmas of five families pondering the decision of whether to list their children for a transplant, the chapter illustrates the moral economy underpinning the heroic use of high-end technology to 'save life' on the brink of death. Framed as stories that are about choices, the experiences of these families sit at the intersection of different technologically informed forces. On the one hand, the therapeutic expectations of the transplant push people to invest on uncertain promises in the face of high risks. On the other hand, the very framework of choice is forced upon people by the technological possibility of prolonging and sustaining terminal conditions.

To explore how people navigate these decisions, I draw on parents' narratives. I weave together the narratives of the five families and complement them with excerpts from interviews with other patients to construct a narration that reflects the ways people presented their stories to me. The emotionally charged style of the narration and the emphasis on seemingly contingent events that turned into decisive turning points are the narrative strategies through which people highlight key passages in their stories. I construct the ethnography around these pivotal moments, where decisions are made and events occur that can potentially lead the story down radically different paths, and remain close to the style and structure of the narratives as they were presented to me. In doing so, I do not use the narratives to question the factual truthfulness of events, but draw on them to introduce the reader to the overwhelming sense of uncertainty, resolution and hopefulness that they convey. The stories illustrate the moral and affective investments that the technology engenders and how these define critical cases as lives that need to be saved. From this perspective, the chapter can also be read as a counter part to Chapter 6.

## “It Was Not a Common Disease”

One day in October 2008, Arai Yoshinori, a salaryman in his late thirties, took his daughter Kaoru for a routine visit to the children's clinic near their home in an elegant West Tokyo residential neighbourhood. Listening to the girl’s heart, the physician found something strange. “It’s most probably nothing,” he reassured them, “but you might want to go and see a specialist at the nearby hospital.” They thus drove to Hospital S, a well-known institute for cardiac disease some twenty minutes away from their home. There, a paediatric cardiologist gave Kaoru a closer examination, including an ECHO test. This showed that her heart was over dilated, a condition that was weakening its ability to contract and pump blood throughout the body. This is known as Dilated Cardiomyopathy (DCM).

Upon returning home that night, Arai-san told his wife about the diagnosis, and together they searched on-line for more information. That first consultation with the doctor had left Arai-san with quite a few doubts, but it didn’t take much research to understand that DCM “was not a common disease (*futsū no byōki ja nai*): it was not one of those diseases you occasionally hear someone has.” Surfing on-line, they read that the prognosis was very poor and until recently most patients died within few years of the symptoms' appearance. The physician told him that drugs were available to slow down the disease's progression, but treatment was merely symptomatic and could not reverse the disease process. If this was to progress too far, Arai-san read on-line, a heart transplant would be the only treatment option.

The day after, Arai-san was back at the hospital. “I wanted to ask again, one more time. It was all too confusing. Too far from everything we knew.” The doctor confirmed what Arai-san had read, and further discussed the information about the drug treatment and explained any possibility of stabilising the condition really depended on the patient’s responsiveness and varied from case to case.

Kaoru was put on medication and the family returned home. By small degrees, the girl’s life began to change. A few weeks into the therapy, she started to feel unwell, and was told to limit physical activity; so she had to quit

ballet and her parents proposed that she take piano lessons instead, but this soon became too physically demanding. At first she skipped PE classes, and then started to miss school more and more often, and soon rarely left the house.

A couple of months after their first hospital visit, taking advantage of the Christmas break, the family booked some days at a hot springs spa in order to spend some time together. One morning, as it was getting late and the kids were sleeping in, Arai-san went to wake up Kaoru and her brother. He found the girl could barely move, and leaving behind his wife and son, he quickly got on the first bullet train to Tokyo and took Kaoru straight to Hospital S. The doctors found that the girl's condition had further deteriorated, but they discharged her for the night and told them to return the following day, when their attending physician would be on shift. The rest of the family had returned home as well, so the day after Arai-san went to work and his wife took Kaoru to the hospital for what he thought would be just a visit like the others. This time doctors decided instead to hospitalise the girl.

The physician told the family that Kaoru would probably be able to return home in a few weeks time, but by mid-January her condition had further deteriorated and it became evident that the drug therapy was proving ineffective. The Arais were told it was necessary to change protocol and they would be referred to a bigger hospital, and on this occasion they first heard about another girl, who had been treated at Hospital S for a similar condition and later received a transplant in the U.S.A. Her name was Sato Aya, she lived in their neighbourhood, and had been roughly the same age as Kaoru when she arrived at Hospital S.

The story of Aya's transplant began with a case of pneumonia. In the spring of 2006, a few kids from her school fell ill, but Aya seemed to be taking too long to recover and so her parents, Sayaka and Junatro, took her to their local physician for a visit. The doctor found traces of blood in her urine sample and referred the Satos to a hospital for further tests. Sayaka and Junatro booked a visit to a medical centre near their place of work, in central Tokyo, "without giving it much thought: we just assumed it was nothing." At the hospital, Aya was seen by various specialists, including a cardiologist who detected a

problem with her heart. The doctor mentioned a few possible diagnoses, but eventually referred them to Hospital S for a more comprehensive examination.

"At this stage, I though it must be a misdiagnosis. I though it was just not possible." Bounced from one specialist to the next for further exams, Sayaka and Juntaro began to get the feeling the situation was serious. At the time, Sayaka said, they were in denial. They looked on-line for information about the diseases the doctor had mentioned and a few days later they were at Hospital S once again. The physician who saw Aya was unable to give them a diagnosis and asked them to return in a few days, when the results of the tests would be ready. In hindsight, Sayaka read her meeting with the doctor at Hospital S in a way she could have not imagined at the time: "I think the doctor recognised soon what it was. But he didn't want to tell us on that first visit because it'd have been too shocking."

When the tests were finally ready, they confirmed a diagnosis of Restrictive Cardiomyopathy (RCM). Like for DCM, the treatment for RCM can only slow down the disease's progress, which in paediatric patients can be extremely unpredictable and can rapidly turn from a condition of stability to terminal heart failure. The only therapeutic option would have been a cardiac transplant, but the Satos were informed that this was not available in Japan. Sayaka described how she gradually almost stopped hearing what the doctor was saying and she just heard that the only thing left to wonder was how much time they had left: "The message I got was that we had no more than six months, maybe one year. The only way [to save her] would have been a transplant, but they didn't do it in Japan. The main shock was the prognosis of one year."

## "We Had to Do it Our Own Way"

When they were finally given the diagnosis, the Satos were told that because of the poor donation rate and the legal clause on cadaveric organ donation, heart transplantation was not a practicable solution in Japan, although clinically speaking it would be the best treatment. If they wanted to go ahead with it, they

would have to go abroad, but Hospital S had no connections with overseas clinics to refer them to.

If the Satos wanted to pursue a transplant overseas, they had first to find a bridge doctor, someone who has contacts abroad to arrange for the girl to be accepted by a transplant programme overseas, a decision that ultimately rested on the hospital committee. Secondly, and no less importantly, they had to find the money to pay for the medical expenses, as Japanese insurance programmes don't cover the cost of care received abroad. To this, they had to add the cost of travel and stay in the country, a total of as much as several hundred thousand pounds (GBP). A considerable potion of this, depending on the directives of the overseas hospital, had to be paid in advance in order be granted a medical visa.

To Sayaka, who until a few days before had been clinging to the possibility of a misdiagnosis, the situation seemed overwhelming. "It was like being abandoned. To me, it was like being abandoned." Not only were they faced with the sudden news of their daughter's life-threatening condition, but for the first time they were in a position where they could not rely on the very system that was supposed to deliver the care they needed. "There was no real way visible to us," Sayaka told me, "they told us that a transplant was the only solution, but we might have to go abroad, as it was not available in Japan, but they didn't even know to which country!"

While the option of the transplant was broken suddenly to the Satos, in contrast it was Nakajima-san herself who proposed it to her physician. Nakajima Mariko was in her late thirties when she had her third baby, Takeshi, a son after two daughters. After a pregnancy free of complications, at the moment she gave birth Mariko, she was told that the baby was unlikely to survive. As it turned out, the child suffered from a rare heart condition, known as single ventricle (SV). This could have been revealed though a pre-natal test that, however, was not routinely performed on low-risk pregnant mothers, and had therefore gone undetected until the child was born.

Soon after the delivery, the doctors told Mariko that the baby had been put on life-support and was in immediate danger of dying. Mariko remembered that

the doctor began listing a series of complications that the boy had which she could hardly count, let alone understand.

Takeshi was eventually moved to a hospital better equipped to treat his condition. At the age of two months, he underwent his first heart surgery and spent the next two months in an intensive care unit where Mariko could visit him for fifteen minutes per day. His second intervention took place when he was two and a half years old. This time, the doctors said it was a success.

Not too long after the second surgery, Mariko's father died. At the funeral, some family and friends noted that Takeshi didn't touch any food and looked very weak. They thought he might be distressed, but nonetheless spoke to Mariko about the child. The day after the funeral, Mariko and Takeshi were at the hospital for a post-operative visit that had been scheduled months before; a good occasion, Mariko thought, to have Takeshi checked. To the surprise of their attending physician, Takeshi's condition had deteriorated very rapidly and the boy had entered the stage of acute heart failure.

Takeshi was soon hospitalised and put on life-support. "But I didn't give up", Mariko told me, knowing in hindsight that there was still quite a lot to come. It was at this time, she said, that she remembered a fellow patient, a baby girl who was also treated for a heart condition at the same hospital. The last time they had met, while Takeshi was recovering from his second intervention, the girl was about to leave for the U.S.A. for a transplant.

> I thought of it myself; it was not the doctors who brought it up. I knew this patient; she had written me a letter just a few weeks before Takeshi got ill to say she had come back from the States. For her it was the first heart surgery, while my son had already had two operations, so I was afraid it might not work out well for him. But I knew Takeshi wanted to live, so I decided I had to do everything that was possible to help him.
>
> (Nakajima Mariko)

Nakajima-san talked about the transplant with her doctors. The local hospital couldn't arrange to get Takeshi listed for a transplant overseas, but they offered to help her make contact with bigger medical centres that could have the right connections. This channel gave no results, and so Mariko directly contacted the mother of the baby girl, who gave her the name of Maeda-sensei, from Hospital

J in Tokyo. Mariko's physician helped her get in touch and arrange a visit. This was September 2007; three months later Mariko and Takeshi left for the U.S.A.

As for the Satos, after their last visit to Hospital S, they started to look outside for help. At first, Juntaro contacted the JOTNW, but it proved a useless attempt, as the agency only deals with national transplants and, given the conditions, there was no chance Aya could receive a heart in Japan. The Satos contacted various patients' organisations with similar results. Finally, they booked an appointment with Ashida-san from the Network of International Transplantation (NIT) Japan, an association they first heard about from their physician at Hospital S.

> And so we went to Ashida-san. At the time we still didn't know which doctor to ask or so. Actually, we didn't even know that sending these kids abroad is the private effort, so to speak, of individual doctors. It was when we went to NIT that we were presented with the doctors. The choice was basically between Hospital J [with Maeda-sensei] and Endo-sensei. Soon after that meeting at NIT, we had the chance to know Endo-sensei in person. We also went to Hospital Q. We talked to Kitaguchi-sensei too, but we decided not to meet Maeda-sensei because my husband didn't want to remain in Japan [while Aya and I went to the U.S.A.] and that's what Maeda-sensei is known to advise his patients to do.
>
> (Sato Sayaka)

Sayaka and Mariko's stories are revealing of a first important aspect of the *tokō ishoku*: the fact that it is arranged through a "*process of subsumption to the health care system through derogation from it*" (Yamazaki 2007: 196; emphasis in the original). Commenting on this, Yamazaki argues that candidates have to reassess their role as recipients of health care and to resort to autonomously looking for ways to access treatments that are not on offer, and therefore highlights the element of contingency (*gūzen*) in the dynamics of seeking care (*ibid*.). Reynolds Whyte et al. (2013) describe similar dynamics in the ways people negotiate access to AIDS care in Uganda through networks of personal connections and influence, drawing a picture in which contingency becomes almost synonymous with precariousness. Certainly, for as many patients who manage to get to the U.S.A. and come back with a new organ, there are as

many who cannot even make it into Maeda-sensei's consultation room or to the office of NIT Japan, and for whom a transplant never even presents itself as a possibility. In the case of *tokō ishoku*, however, contingency can be looked at from various angles, and, as I show below, patients' capacity to move between different nation states, jurisdictions, and health care systems can maximise their chances of obtaining fast and safe care (cf. Chapter 3). In this sense, contingency cannot mask the fact that the networks that people rely on in becoming *tokō ishoku* recipients are in fact highly systematised.

What I want to highlight here, however, is another aspect of the problem. As will become clearer through the ethnographic data, the contingent nature of the process of treatment seeking is strongly emphasised in the patients' narratives. Being admitted to a certain hospital, knowing a certain patient, being referred to a certain association, attending the right meeting at the right time, are all moments described as both accidental and crucial in the realisation of one's treatment options. From the patients' perspective, at least during the process of seeking care, contingency results in a life-threatening precariousness, and further exacerbates the already uncertain nature of the clinical path.

## "The Private Effort of Single Doctors"

It emerges from Mariko and Sayaka's experiences, that it is individual surgeons and physicians who negotiate patients' access to the waiting lists for an overseas transplant. They are the key subjects in the *tokō ishoku* system, and several of them worked as mediators in the majority of cases I came to know about.

Kimura-sensei is one of these mediators. He is also an international star whose notoriety is telling of the special charisma that surgeons have (and transplant surgeons in particular after Barnard) as pioneers at the forefront of the enterprise of saving lives (Fox and Swazey 1978). After graduating from Osaka medical school, Kimura-sensei moved to the United States on a

fellowship in transplantation, and went on to have a brilliant career in some of the most renowned centres in the country. As even a quick search on *Google* will reveal, Kimura-sensei is a world-leading figure in liver and intestinal transplantation. He has performed never before attempted multiple organ transplants and experiments on how to translate transplantation techniques to a variety of clinical problems that are not traditionally treated through organ transfer.[29] His work has earned him worldwide notoriety. He has a Wikipedia[30] page that notes, "he is author or co-author of more than 180 scientific papers", but his popular fame might even outgrow the academic one. From *YouTube* to the *New York Times* (2009b), from the American television channel ABC to Japan's NHK, the story of this Japanese surgeon has fascinated the international media. The most recent case is a *manga*[31] based on a popular book he wrote about his job, in which he features as an attractive and idealistic young doctor nicknamed "Guy" to refer to the fact that he went abroad (*kaigai tokō*, as in *kaigai tokō ishoku*).

Another Japanese surgeon who went abroad is Dr. Kitaguchi. He considers himself a self-made man, and his choice to leave Japan fits his daring ethos. He told me he had wanted to be a cardiac surgeon since he was young and lost his sister to heart disease. Unsatisfied with the nepotistic Japanese medical world, he left to try his luck abroad. Soon after graduating he moved to Germany for a fellowship and ended up staying more than thirty years. He was trained as a cardiac surgeon there, married a German woman, and spent most of his career at a well-known university hospital. Their transplant programme dates back to the 1980s, when only very few centres worldwide were performing such interventions, and over the years it developed a high volume of patients from various countries. Thanks to Kitaguchi-sensei and his contacts in Japan, such as Ashida-san, many Japanese patients have been treated there too, the last one not long before my fieldwork.

Meanwhile, in 2005, Kitaguchi-sensei had moved back to Japan with the dream of setting up a heart transplant programme at a famous university

---

[29] One such example involved the en-bloc transplant of organs in order to intervene in tumours that would be inoperable within the body.
[30] http://en.wikipedia.org/wiki/Tomoaki_Kato
[31] GUY: 24 hours in the transplant unit (Andō and Kato, 2012).

hospital in Tokyo. The project was aborted when, he told me, the dean changed. Kitaguchi-sensei privately funded his own association for the promotion of transplantation in Japan, through which he regularly organises promotional and educational events. He also writes books about his profession, and generally seems to enjoy the contact with the public and with the patients he took to Germany, who have regularly kept in touch over the years. After the missed opportunity with the university hospital, he was appointed as head of the cardiovascular centre at an important hospital in an inner region of Japan. The hospital, however, is not listed as a transplant centre by the Ministry of Health Labour and Welfare (MHLW) and so Kitaguchi-sensei has in fact stopped doing transplants since he has returned to Japan.

Endo-sensei works instead at one of the Japanese transplant centres known to be traditionally more proactive, Hospital H, second in the country for the number operations performed. He is one of the best-known figures in the field of paediatric cardiology in Japan and, together with Maeda-sensei, is considered the contact that can provide the fastest way to get on the American waiting lists for a new heart because of his good connections with hospital R in the U.S.A., a world leading centre with a pioneering history in infant cardiac transplants.

His interest in transplantation started, he told me, when he was an elementary school student and heard about the Wada case in the news. Without being able to grasp what he now judges as serious ethical problems, he was struck by the news of what seemed almost like sci-fi medicine. In the early 1990s, he spent two years at Hospital R specialising in paediatric heart transplantation and researching xenotransplantation, which he is convinced could spell the end to the problem of organ shortage if only surgeons were free to experiment with it more consistently. Endo-sensei is clear, however, about the fact that he didn't go to the States to "learn" transplantation and take it back to Japan, his aim instead was developing "transplantation Japanese style." As part of this plan, soon after he returned from the U.S.A. Endo-sensei actively engaged in lobbying the government to legalise brain death in the country, but this is another story (see Chapter 5).

While he was still in the U.S.A. and cardiac transplantation was still unavailable in Japan, a patient from his hospital, Hospital H, became the first Japanese candidate to travel to America for organs. Once back in Japan, it was Dr. Endo himself who started to arrange to send his patients overseas. He still remembers the exact date when the first of his *tokō ishoku* patients received his transplant, and after more than ten years it is still a tradition for the two of them to compete together at the badminton tournament of the annual Transplant Games.

Maeda-sensei, however, is rarely seen at such events. He is famous for being quite a reserved man, even a little strict, and even the patients who have been under his care for years speak of him with a mixture of affection and reverence. Every year, he runs a public transplantation seminar, which has become a traditional occasion for his patients to meet up.

Maeda-sensei is not a surgeon but a physician. He is based at Hospital J, in Tokyo. In the early 1990s, he had just taken up the position, upon returning from a fellowship in the U.S.A., when he met Nagahisa Mika and his parents. Mika was treated at Hospital J for DCM, the same disease her older brother had died of. She was already in a serious condition when she was transferred from her hometown's smaller hospital to Maeda-sensei's centre. Even there, however, there was little they could do to help her. Maeda-sensei thus brought up the possibility of sending her to America. There had already been a couple of patients who had travelled overseas for transplants. Maeda-sensei, however, had no experience of doing such a thing, and although he could count on the support of his boss at Hospital J, he was only at the beginning of his career. To make things more complicated, Mika's condition was not promising.

"My mum and my family asked Maeda-sensei what my chances of recovery were if I went to America [and received the transplant]. At that question, he just looked down at the floor. He couldn't reply. He couldn't even advise my parents about how much luggage they needed to prepare." Mika, just seven at the time, was not fully aware of the risks involved. Her parents later told her that Maeda-sensei himself couldn't tell how long they would have to stay in the country; months if she was lucky enough to have to go through

post-operative rehabilitation, or just a few days if she got worse on the journey and a donor didn't become available soon. "We really fumbled our way through until the end (*zutto tesagari*). Me, my doctor, and all the people involved."

This brief introduction to some of the most prominent surgeons and physicians in the field of *tokō ishoku* provides an initial picture of the networks that give shape to transplant patients' mobility across international borders. At the same time, the life trajectories of these medical professionals offer glimpses of the ethos driving the transplantation enterprise. Besides the rhetoric of ambition already mentioned, success and charisma that feed the public accounts of their careers, the story of Maeda-sensei's first patient's experience tells of other aspects of the moral economy that upholds the *tokō ishoku* enterprise. Gordon has analysed for example the dynamics of patients' transplant choices, emphasising the ambiguities and uncertainties medical professionals encounter when they list marginally suitable recipients (Gordon 2000). In contrast to her discussion, the cases of *tokō ishoku* I encountered present instead situations where the balance between the possible risks and benefits of the decision to resort to so-called 'extreme measures' becomes a moral imperative.

The patients' youth and the immediate threat to their life heavily inform these decisions. At the same time, the close relationship between families and doctors, forged through prolonged care as in the case of Maeda-sensei and Maki, or dependent on the desperate plight of families to whom the individual doctor is the last hope, also lingers in the decision. What makes these imperative decisions so compelling in the face of uncertain outcomes, is the possibility of rubricating the risks at stake as only partially related to the clinical assessment of the patient. The outcome of the decision ultimately depends in great part on how long parents will need to find money they need for the visa, if a donor will become available on time, and if the patients' condition won't deteriorate too far because of the journey. These are all elements physicians and families have no ethical responsibility for. The decision becomes imperative, and at the same time requires undertaking high risks in the attempt to save life.

Saving lives (*inochi wo sukuu*) is indeed like a mantra in the field of *tokō ishoku*. It is the motto of associations like NIT Japan, is invoked by patients' families in their narratives and even returns as the slogan of the fundraising campaigns parents organise to collect money for the medical expenses. Indeed, *tokō ishoku* is an extreme instantiation of the desperate attempt at saving lives that drives transplantation medicine, and heroic medicine more generally (cf. Wailoo and Livingstone 2006).

In Mika's case, the effort paid off. She received her new heart shortly after arriving in the States, and more than twenty years after she was still doing well. As the first paediatric patient from Hospital J to receive a transplant in the U.S., her experience was somewhat peculiar, but the sense of uncertainty she reveals in her narrative ("we fumbled our way through") is not unique to her story. The following sections look at the moral economy of clinical decisions that concern a therapeutic path so deeply informed by uncertainty.

## "If This is the Only Way"

After the meeting at NIT Japan, Sato Juntaro had made up his mind to trust their chances to Endo-sensei's connections with Hospital R. His wife, however, was less sure, and while they were already making arrangements with the American hospital she still wondered whether there wasn't another way and even consulted a renowned centre of Chinese medicine in Tokyo. The fact her husband was very proactive maybe gave her the space to articulate more openly what were probably shared concerns about the choice of going ahead with the transplant. The more they read about it, the more she got worried about what kind of life they were pursuing for their daughter, "both medically, and morally."

> Other people's organs? Is it ok to want to live so much to take other people's organs? […] We read quite a lot of these comments on-line, and we started to have doubts. We didn't know anyone who received a transplant or any similar therapy; we really didn't know anything.
>
> (Sato Sayaka)

Recalling her doubts, Sayaka voiced what seems to be a common concern among Japanese potential recipients (see also Tomomatsu 2013). Mika too remembered that her case attracted similar critiques: “People criticised me because I wanted to live so much I’d go to the lengths of receiving another person’s life instead of accepting my own death”. For none of the patients I interviewed, evidently, such moral concerns became a reason to opt out from the transplant; still, the doubts they told of, the opposition they feared from the public or even members of their own family, and the concerns they voiced about cadaveric donation are revealing of the ethical landscape they moved in. Contrary to the celebratory rhetoric that depicts transplantation as an almost miraculous cure, in Japan much of the debate on this technology revolved around the issue of brain death. Public propaganda around organ donation and transplantation is now part of the public discourse, and indeed in the space of just one generation the possibility of a prospective candidate accessing information about treatment has tremendously improved (cf. Chapter 5). On the other hand, the testimony of young patients’ families reveal how the brain death controversy still has an enduring legacy in the ethics of transplantation in Japan and of how the specific local history of the technology can inform treatment decisions (Rapp 2000).

Other concerns that the patients’ parents express resonate more closely with the experiences of prospective recipients from other countries and reflect the uncertainties of the clinical path (cf. Maynard 2006). Transplantation is a complex treatment characterised by a systematic approach to diagnostic, surgery, risk-benefit assessment and post-operative care. To be eligible, patients must be ill enough to need it and healthy enough to survive it. Even when this is the case, it only means that the surgery was a success; quite tellingly, the clinical success of transplantation is measured by survival rate.

‘Survival rate’ is a phrase that enters the discourse of recipients as soon as the option of transplant is first proposed, and to Izumi-san they were the most frightening part of her decision to list for the operation. Izumi Midori knew from the time she was young that a transplant might eventually be the only treatment for the rare liver disease (PFIC) she was born with, but this didn’t

prepare her for the decision she had to take when she actually entered the stage of organ failure and had to decide whether to list for the operation in Australia.

> One day, when I had already been transferred to Hospital J [for its transplantation program] my physician explained to me about the survival rates. I got very anxious thinking what could happen to me. He told me that almost 80% of the recipients make a full recovery and return to society (*shakai fukki*) […] [But] it was a shock for me, because I had no way to tell which group I'd end up in: those who survive or those who die? If you think of it not just in terms of numbers, if you really put yourself in the position of being one of those numbers, that's very scary. I had a 50% chance: it could be either one or the other […] I was scared by the fact of not knowing. I didn't even know what to fear, what to worry about. All of a sudden it was either life or death, and I had no way to tell which one would be my fate. I didn't even know what I should be afraid about, what I should be scared of; it was just all encompassing. There were not many Japanese recipients [at the time]. It looked almost like a human experiment.
>
> (Izumi Midori)

Significantly, when faced with the 80% survival rate, Izumi-san felt she had a 50% chance. Whether positive or negative, possible outcomes were absolute. Fear was gripping her in the face of a treatment that, she felt, left no space for degrees of success.

Twenty years on, Midori was in her forties and a housewife. Apart from frequent follow-up visits, she was hospitalised several times and her condition was no longer as good as in the first years after the operation when, she proudly told me, she ran the Transplant Marathon. Whether this was the "full recovery" she envisioned I cannot tell, but even though she never put it in terms of a regret, I think she somehow resented her health problems, that got in the way of having children. However, she was very positive about her life after the transplant and the treatment itself. She was clear about the fact the transplant didn't only get her twenty more years, but changed her life for the better compared to the discrimination she suffered at a young age because of her disease. She was very keen to spread a positive message about the

efficacy of the treatment[32] as a way to help other patients, as she recounted how the lack of such a system of support and the possibility of sharing information with other patients made her decision much more difficult.

Midori's story deconstructs the uncertainty of clinical choices usually framed as a matter of risks *vs*. benefits. Regardless of the statistics about the 80% full recovery, she felt like she had 50% chance of not making it, because, as she put it, "it could be either one or the other." Possible outcomes, whether positive or negative, appear absolute and sharply polarised, leaving no room for degrees of success. At the same time, the ideal of "full recovery" (*shakai fukki*) opens horizons of uncertainty in the long run, calling into question the so-called problem of patients' quality of life.

Such were the fears Sayaka had for her daughter, as they looked more deeply into what the transplant practically entailed. As she recalled:

> We did a lot of research on-line and there was not much positive information about transplantation. It didn't look like a bright way to go […] I was afraid that she might not be able to do this or that; that she'd end up in and out of hospitals most of the time […] The thing is, there was nothing else we could do.
>
> (Sato Sayaka)

Her husband, Sayaka told me, was more resolute. "He was quite good at deciding. 'If this the only way' he said 'we're going to do it.'" Without wasting too much time he quickly got together a group of friends to help raise money to pay the hospital and get a visa. A few weeks after they had the diagnosis, the Satos gathered together all their relatives from both sides of the family and announced their decision to take Aya to the U.S. for the operation.

What Sayaka remembered most strikingly about her husband's decisiveness ("if this is the only way, we're going to do it") points directly to the core of her dilemma: the problem wasn't that there was nothing else to do, but that there was this particular option to pursue. In clinical decisions, the idea of risk is used to make sense of this impulse for saving lives: framed as

[32] She even published a *manga* about her story to promote organ donation and often participated in public events about transplantation. More on this in Chapter 5.

calculated risks, clinical decisions are construed as informed consent and as an act of agency in asserting one's capacity to understand and (attempt to) control one's fate. The story of Sayaka somehow complicates this view. It shows that risks are such when they can be taken, and when they are the uncertain alternative to a certain death. Her story shows how technology itself is a generative practice, for its very existence produces the moral imperative of exhausting all the possibilities to save life. Consequently, it demands ways to organise a moral economy that make sense of the risks it imposes.

## Treatment of the Last Resort

After Kaoru was hospitalised for what was supposed to be just a couple of weeks, her condition worsened further, to the point where she was in severe pain. The family was referred to a more specialised facility, and the Arais were told they had to change protocol and decide on what clinical path to follow next.

> We had to consider treatments of the last resort. The transplant was one of the possibilities, but we'd have to go abroad for that. The other option was to stay in Japan, as some choose to do […] If we stayed, we'd have go on with the [drug] treatment, but we didn't know for how long that would have been possible for the chances to stabilise her were really unlikely […] As for the transplant, I didn't even know how long one can survive after it. You get through such a difficult operation and then how much time do you have? Six months? One year? I had no idea. When I was a child, well it was quite a while ago, but I remembered the news of transplant patients dying soon after the operation. I had such dreadful thoughts about transplant. If it's just about gaining a few months or years…I mean, is it worth spending your last time in a hospital bed? Aren't there options to be better than that? In the end it was also about the quality of the last time she had to live. There were treatments to keep her in a decent condition, although she'd have not been able to leave the hospital. We were also given the option of palliative care, to try and alleviate her last months. I then had a look at the statistics about transplant: 75% after five years; 50% after ten. But they take into account only those who survive; there are also those who die for the operation. Looking at the data together, the doctor told me he wouldn't have done it […] Personally, I didn't know anything about it (*shiroto*).
>
> (Arai Yoshinori)

The Arais' experience reveals other aspects of the clinical decision. Whereas Aya's disease threatened to suddenly precipitate but remained stable until the end, Kaoru's condition was slowly but irreversibly degenerating. Sato-san made up his mind about the transplant with his daughter out of hospital and in relatively good health, and indeed their fear was that she would not be able to return to such a condition after the operation. Arai-san, on the other hand, had to decide how to treat a child who was already in pain, unable to drink or eat and dependent on life-support. For him, the distinction between quality of life and quality of the end of life was much more blurred.

The Kumanos found themselves in a similar position within a matter of months. In June 2008, their only child, Shuichi, a baby boy with deep black eyes and plumps cheeks, was diagnosed with DCM and admitted to hospital. After that, his parents' routine revolved around the medical facility. Natsuko was a nurse herself. She was on maternity leave when Shu-chan[33] fell ill, and she spent all her days with him, quickly bonding with the medical staff attending to the child. Her husband Keisuke was in his mid-thirties and worked in Tokyo. Every evening, after work he made it to the hospital for a visit, and stopped for a quick bite at a restaurant next to the hospital on his way home.

Doctors had told the Kumanos that there was a possibility Shuichi would develop heart failure and need a transplant. For their part, the Kumanos thought that until the doctors brought up the issue again it meant they were not there yet. In the meantime, however, Shuichi was rapidly deteriorating. After a while, he was moved from paediatrics to the ICU. He became unable to move, eat or drink. In the pictures Natsuko took, he looks skinnier and weaker as the weeks passed, until he was attached to the oxygen tube that the nurses had stuck to his face with bandage cut into cute shapes of animals to prevent him from removing it. Natsuko and Keisuke were clinging to the hope Shu-chan would get better.

One day, a couple of months after Shuichi was admitted to the hospital, a nurse approached Natsuko, and with the directness that comes from

[33] *-chan* is a diminutive suffix that conveys endearing feelings and is normally used for young children.

confidentiality she broke the question of the transplant. It was then, Natsuko told me, that the impending decision changed their perspective and made it clear Shuichi was terminal.

Compared with the Satos' experience, the stories of the Arais and the Kumanos cast light on the very conceptual frame that organises the therapeutic experience around decisions. Writing about this, Mol (2002) argues that the language of decisions:

> [S]eparates decision-making moments from the series of long-layered and intertwined histories that produce them, as if somewhere normative issues could be isolated and contained within those pivotal points. As if they were, indeed, pivotal points. […] Every single moment always hides endless contingencies – which, if one looks at them carefully, are likely not simply to be contingent. That means that most elements relevant to making or unmaking the goods of life involved in making a decision escape the moment of that decision.
>
> (Mol 2002: 170)

From this perspective, the Arais and the Kumanos' experiences add a further, crucial, and yet often overlooked dimension to the discussion developed so far. Not only must decisions be understood in the context they are taken, but the very possibility and modalities of what can be decided define what is at stake. One would think that the 'treatment of the last resort' is that which becomes necessary when the condition is terminal, but the opposite is also true: in people's lived experience, having to decide is what defines the condition as terminal and prepares those involved for what comes next (cf. Chapter 6). Closely related to this is the fact that the very possibility of treatment defines the condition it targets, from terminal in the sense of hopeless, to terminal as in requiring immediate intervention.

## "No Regrets"

After the talk with the nurse, the Kumanos embarked in a process of further consultations with doctors and various specialists about the risks and practicalities of *tokō ishoku*. In hindsight, Natsuko had no space for doubts, but

she acknowledged that the lack of better alternatives didn't make the choice any easier.

> It is not about the choice in itself; it's about how you think that choice is going to affect the person's life. The concerns about the transplants and the decisions families have to make are very significant in these respects. It's all about what can you do and how far you can go, as a parent, for a son who cannot even speak for himself.
>
> (Kumano Natsuko)

The cases discussed present especially sensitive bioethical dilemmas because these decisions affect people who cannot exercise control over them[34]. While extreme in this regard, these cases are also revealing, through the close bond between decision-maker and patient, of more general characteristics of clinical negotiations. Clinical decisions are always a process, more than an event, managed within a group of people, including the patients, his/her significant others, medical practitioners, and social mediators (cf. Chapter 6). In theorising diagnosis and therapy as processes negotiated by "treatment management groups", Janzen (1987) explains this perspective enable us to see patients' problems as more gradual and chronic than the occasional encounters with medical experts would suggest. The same could be said about the clinical decision, which here appears to unfold through a process of lengthy negotiations. Furthermore, as Natsuko's comments suggest, these decisions bear implications for the future life of all those involved, as both the patient and the family will have to live with the outcome of these choices.

From this perspective, the ways in which people structured their narrations, through well-rehearsed patterns, reflect how they used narratives to re-organise significant episodes of illness and reconcile their outcomes (see Kleinman 1988). In Arai-san's account, this aspect emerged particularly from the emphatic shift from his initial indecisiveness to his later decisiveness.

Physicians had told Arai-san that they had to transfer from Hospital S to a university hospital that could offer more specialised care and Yoshinori was in

[34] See for example Davis (2010) for a discussion of the dilemmas of medical choices (in this case on genetic testing) when these shape the lives of children, sometimes before they are even born.

the process of checking various institutions when he met Kanemaru-san. Kanemaru-san –or, as Arai-san called her, “the old lady”– was the mother of a former patient of Hospital S. Since her daughter was diagnosed with a cardiac disorder more than twenty years earlier, she had been volunteering with the Association for Children with Heart Disease (ACHD) and became a sort of reference point for families considering transplant overseas. When she knew that Arai-san, who had attended a couple of meetings of the ACHD, was in the process of considering a transplant, she offered to introduce him to “a good doctor” and invited him to Maeda-sensei’s seminar, which was conveniently scheduled in a few weeks time.

> She told me there would be a lot of healthy patients, who had greatly benefited from the transplant. Honestly, I didn’t quite believe it. The doctor had been so negative about it, and those statistics too [were not too encouraging]. Of course, the old lady told me, there are risks involved. But she also said that when it goes well, people can recover completely, get normal lives, a normal job. So she asked me to consider these positive things too, and try for once to look at it from a different perspective; like re-setting my mind.
>
> (Arai Yoshinori)

Arai-san made it very clear that he and his wife were sceptical and even slightly suspicious about the old lady’s promises but nevertheless decided to go.

Various patients were present, including Takeshi, who had just returned after a successful operation. Arai-san talked with Nakajima-san and other families of *tokō ishoku* children, and listened to their presentation about their experiences. Towards the end of the event, the old lady introduced him to Maeda-sensei, and Arai-san showed the physician Kaoru’s clinical records that he had brought with him. At that point, Arai-san said, the old lady abruptly jumped in asking Maeda-sensei if he had read the papers well. Yoshinori thought it was very rude to interrupt the doctor like that, but didn’t give it much thought. Only later, he said, he understood the old lady must have seen enough patients to know Kaoru might not make it for the transplant overseas.

In three days, the Arais moved to Hospital J under the care of Maeda-sensei. The girl was serious and needed artificial ventilation. If they opted for

the transplant, she would have normally been given a so-called artificial heart, a mechanical device used to support patients through the waiting time and bridge them safely to the operation. The device, however, was not available in Japan[35], because heart transplant was not on offer, and this made even more urgent the need to quickly arrange for the operation overseas. Maeda-senei discussed the situation thoroughly with Yoshinori and his wife and gave them one week to decide whether to go ahead with contacting the American hospital.

> During that week many people advised me, and I myself did lots of research, but in the end it was at the seminar that I really made up my mind. It was not something I heard or something I was told, it was real facts. And that was a possibility we had. It might be hard, but as a parent, if you know you have such a chance, you cannot choose to let her die. Seeing those healthy patients at the seminar really changed my stance about it, as a parent. It became my motivation (*dokidsuke*). […] It gave me the courage to act. I thought we had to do it.
>
> (Arai Yoshinori)

Only a few months later, Maeda-sensei was advising the Kumanos about the risks involved in the transplant overseas. Natsuko and Keisuke had made up their mind for the overseas transplant, and their physician put them in touch with Endo-sensei, thinking that his good connections with Hospital R, one of the major transplant programmes in the U.S.A., was likely to ensure a shorter waiting time for them. One day, they received an email from Endo-sensei, who offered to introduce them to some his patients so that they could hear about *tokō ishoku* from those who had gone through it themselves.

A few days later, Natsuko left Shuichi alone at the hospital for the first time since he had been hospitalised, and got on a train to Osaka. There, she joined Endo-sensei at the Annual Conference of the Japan Transplant Association, where the surgeon introduced her to some of his patients and their parents, including the Satos. Aya had made a full recovery, to the point that without knowing about her story it would have been impossible to tell she had ever

[35] Paediatric artificial hearts, were not approved for use in Japan until 2009, when organ donation was legalised from patients under fifteen. Paradoxically, the machine was even more needed when transplantation was not available in the country, as young *tokō ishoku* patients faced increased risks whilst waiting for surgery because of the journey and the unpredictable time needed to set up the transfer and the fund-raising.

been sick. Natsuko recalled that first meeting with the Satos as the turning point in her experience. By the time she was back in Tokyo that night, she said, she knew what to do.

> Up to that moment, we had heard only very harsh opinions about transplant. We didn't know whether he would survive or not, whether we wanted to do it or not. Maeda-sensei had warned us that transplant is not something you can make a laugh about. He explained it's not as easy as just receiving and getting healthy. He explained to us that he'd need care afterwards, that it can be difficult, that there might be complications, and that we had to be up to the challenge. But that's only rational knowledge. We understood. We agreed. We were told everything about *tokō ishoku*. We knew how hard it can be for the parents to go through such a psychologically demanding process without even being sure the child will survive. I couldn't quite make up my mind on that, but then I saw how good transplant can be, and I knew we had to do it. It was like a shock. In one second, my view (*kachikan*), all the things I had been thinking in my head, everything changed completely. And that gave me a great energy. It was there that I made my decision. And since then, we grew firmer and firmer in our feelings. That's what we were aiming to: not reducing the pain, but becoming healthy again, getting back to life.
>
> (Kumano Natsuko)

Perhaps unsurprisingly, both Natsuko and Yoshinori organised their narratives so as to emphasise the moment of the final resolution. They both presented the meeting with other patients as the turning point in their decision-making process, and framed this moment as a complete change of mind, shifting from the focus on (uncertain) risks-benefits, to the description of their driving motivation and the sense of fulfilment they derived from pursuing the realisation of their decision. What they are saying is that the decision of listing their children for the transplant was not taken only because of the lack of statistically safer alternatives in terms of risks-benefits, but because it was the right thing to do.

One idea that returns frequently in the narratives of patients' families is that of 'holding no regrets' (*kōkai shinai*). The trope of 'holding no regrets' is telling of the moral investment people make in these decisions. As it projects the choice into the future and anticipates a possible negative outcome, the paradigm of 'holding no regrets' speaks of the need to reassert the worth of the

decision made and to protect the person from the responsibilities that come with it, especially in light of highly uncertain results. Combining the emphatic description of their driving and self-fulfilling impulse to act, with the strategic negotiations of the results that this initiative brought about, Natsuko and Yoshinori's narratives introduce us to the workings of hope in directing decisions where stakes are high and outcomes are sharply polarised.

## "It's Like a Hurdle Race"

Just a few days before her trip to Osaka to meet Endo-sensei, Natsuko and her husband saw Maeda-sensei for a second opinion. As with Mika's parents and the Arais, Maeda-sensei thoroughly warned the Kumanos about the risks involved in the transplant overseas, especially with a condition such as Shuichi's.

Like Shuichi, many patients are already critical when they set off to the U.S.A. By the time families get a diagnosis, find a doctor who can arrange their transfer overseas and raise enough money to leave, patients are often at a critical stage and some don't even make it to their destination. All measures are taken to make the journey safe, like escorting the child to the airport with an ambulance and setting up medical equipment on the airplane; even so, the flight can prove to be further destabilising and cases are not rare of children dying just a few days after they are admitted to American hospitals. By this time many are already high-priority cases; some are put on an artificial heart, but the waiting time ultimately depends on the chances of a suitable match.

Besides the risks strictly relating to the clinical condition of the patient, the family has to be prepared to face significant changes in their life. The fund-raising is very stressful and can expose families to criticism (see more in Chapter 4), while the experience of leaving everything for several months to travel to a foreign country with a sick child can be upsetting for the couple and can be very difficult to manage if there are other children involved. Even when all goes well, the post-operative care is very demanding (see Chapter 3). In this way, the transplant requires the mobilisation of a vast array of financial, social

and emotional resources by those surrounding the recipients (cf. Maynard 2006).

After the Kumanos decided, things rapidly escalated and Natsuko was caught up in the frenetic preparations for the fund-raising and the transfer to the American hospital. Her husband took care of the campaign to raise money while she stayed with Shuichi's at the hospital. The child was very unstable. He had a high temperature, his heart was further deteriorating, and shortly before the scheduled departure he suffered bleeding in his brain. In that condition, they were not even sure he could get on the waiting list.

> Up to the very last week, the very last day, we were told it was an extraordinary thing to bring a child in such condition to America…I wanted to postpone the time of the departure, but it was my husband who decided in the end. He asked the doctor to let us go: in a month he could no longer be there, he said. I felt very confident he'd still be there in one month; I thought he'd be fine. Thinking back now it was very dangerous, but I thought we could to postpone. Everything had been done in preparation for that day: we booked the private flight, contacted the American hospital, set up a schedule with the doctors. They were all waiting for us, and to change the plan, even of just one week, would have been problematic. I understood that in my head, but emotionally…All I could think was: 'This is not the best day for him. Not now'.
>
> But it was decided for that day, and so I pulled myself together and I did it […] I was almost emotionless, as if nothing would touch me (*dodemo ii*). In my heart I was repeating to myself: 'Keep clam, keep calm. It's going to be fine, it's going to be fine. Just another 24 hours, another 24 hours…and if he dies?' I was really scared. It was hard. It was hard for him, but it was also hard for me. The day was approaching, and we had to prepare. But I didn't have the time to go home and pack our things, Sousuke was very unstable, it was difficult to leave him. And still we had so many stupid little things to do. Knowing you might be away as long as one year, you would normally clean the house, empty the fridge, and we needed to pack our stuff. But I couldn't take care of anything (*dodemo ii*).
>
> Anyway, I went home, I did the packing, I took a shower, and I was back at the hospital. I stayed there the night before leaving.
>
> (Kumano Natsuko)

The last passages in Natsuko's narrative unravel the emotional dynamics entangled in a therapeutic path that Mariko described as a "hurdle race". Franklin uses the same metaphor in her ethnography of IVF in the UK to

describe the emotionally totalising experience of a treatment course made up of different stages, each of which can either bring the couple closer to their goal or turn the whole experience into a failure (1997). Similarly, the pathway towards the transplant overseas appears to unfold through a series of critical moments: the diagnosis, the search for the right doctors, the resolution to go overseas, all are presented as key passages in the way events unfold. In the organisation of these, each moment is a crucial turning point. Like Natsuko's last quote illustrates, at each of these steps hope builds up, until the experience of seeking care leaves no space for anything else, not even fear or relief, and seems to become almost self-fulfilling (cf. Franklin 1997). At the same time, however, no one step leads necessarily to the next one. The clinical path emerges as non-consequential, precarious and fragile. It unleashes intense hope, but also requires being carefully managed. As Crapanzano notes, in desperate clinical situations, both the medical experts and the patient have to avoid paralysing hopelessness while at the same time they are forced to ignore, or at least to limit, hope (Crapanzano 2003: 17). The concluding sections below present Yuka and Sosuke's story, which further deconstructs this interplay between hope, uncertainty and the emotionally totalising experience of treatment.

## "Gambatte!"

Yuka was from a well off family from central Japan. She moved to Tokyo when she got married. Shortly after she gave birth to a baby boy whom she propitiously named Sosuke. Soon after being discharged from the hospital, the first problems began. Sosuke suffered frequent attacks of vomiting. Because of the lack of nutrition, he was weak and in poor health. Yuka embarked on a series of consultations with several specialists, until eventually she was given the diagnosis of Hirschsprung's disease, a rare disorder of the gastrointestinal system.

The condition was not operable, and the only solution to keep Sosuke alive was artificial feeding. The child was therefore put on total parenteral

nutrition (TPN), and the intervention to surgically insert the feeding tube marked the beginning of Yuka and Sosuke's life at the hospital (*byōto de no seikatsu*). TPN presented serious side effects and exposed the child to risk of infections from the use of intravenous catheters. Sosuke's condition was never good enough to leave the hospital, and in nine years, she told me, they spent only one day at home and free from medical complications. "The hospital had become the place where we lived and the place where I had to bring up my child."

With time, Yuka told me, she grew more aware of her child's needs, becoming less reliant on doctors and more confident in asserting their priorities at the cost of arguing with the medical staff. She became quite literate about Sosuke's disease, but she also learned there was more to life than that, even in the hospital ward. One episode she particularly liked telling me about concerned a specially equipped wheelchair that she managed to get in order to carry the TPN machine outside of the hospital and take Sosuke for a walk despite the doctors' advice not to leave the room.

Yuka often said that living in a hospital room can be gloomy and depressing, but that it didn't spoil Sosuke's curiosity and brightness. In the pictures and videos she showed me of "my Sousuke" (*uchi no Sousuke*), he is often surrounded by toys, books, pens, a laptop and a great number of objects that all fit in the space of a bed too big for his tiny body. She went to a great lengths to try and make his life as challenging as possible. Food was maybe the most important experience Yuka made him have. Since he was put on TPN, Sosuke could no longer be fed non-artificial food. As he grew old enough to understand, he began asking questions about food and would become upset by seeing people eating around him. Yuka came up with a series of games to make him experience food: she would let him crumb rice cakes and bread to listen to the noise they made, and provide him ingredients to prepare *onigiri*,[36] which she would then eat. At mealtimes, Sosuke usually chose the menu, and Yuka told him what the food tasted like.

Life in the hospital ward, however, also meant physical pain, loneliness, and uncertainty about the future. With time, TPN took a great strain on

[36] Filled rice balls wrapped in seaweed.

Sosuke's body. Shortly after they initiated treatment, he developed a serious infection and entered a coma from which doctors said he was unlikely to return. After that first episode, he underwent several further life-threatening crises, and survived nine years in a 'chronically terminal' condition before listing for a transplant. Because TPN is merely a life-prolonging treatment that couldn't address his underlying condition, the decision to initiate it was fated to raise serious dilemmas in the long run. As Sosuke overcame various life-endangering episodes, it became clear that whether and how to let him die would have to be a consiocu decision.

In her memorial, Yuka describes the years at Hospital W and the constant entering, and recovering from, life-threatening crises:

> In the middle of a crisis I was unable to think, I just focused on being there for him, on encouraging him to be strong and to not give up. But as soon as the situation stabilised, I was caught back again in fear and in the lack of prospects for the future. 'How long can we go on like this? What will come next?' In the myth of Pandora's box, after all the evils have flown away, it is hope that remains. Even if just a little, I wanted some hope (*sukoshi demo kibō hoshikatta*).
>
> (Kakumu 2009:65)

Hope eventually came in the charming figure of transplant star Kimura-sensei. In 2004, the news was reported that a Japanese baby suffering from the same disease as Sosuke had successfully received an intestinal transplant in America, operated on by Kimura-sensei. Doctors had always ruled out the option because the operation would have been too complicated (Sosuke's condition required a multi-organ transplant) and the child was not well enough to undergo surgery. The meeting with Kimura-sensei, on one of the surgeon's frequent visits to Japan, opened the way for the first time to the possibility of curative treatment. Even though the doctors well knew, as did Yuka and Sosuke, that his chances were tiny, they decided to try.

Yuka said that the decision to try and receive the transplant changed Sosuke completely: "he regained his energy and his eyes were sparkling again."

> We didn't even know if he could make it, if a donor would become available. I hadn't explained him about these details. But just the thought that it could work, that he would be able to eat a hamburger [as he always wanted to]. He wanted to get well and be able to eat. It's incredible how people can change just thinking they have a chance. We take for granted we're alive, but it's not obvious at all (*atarimae*). Even though he never really told me, I think in his heart he knew his life was at risk; and I'm so sorry for that […] [The preparation] was tough; it was psychologically very hard. I didn't know how to talk about [organ donation] with Sosuke, so I decided to explain everything to him only once we would be there, because for the time it was already too hard. But even though it was hard, I'd have done anything if it meant having a chance to save his life. I didn't care what it took: it was about saving his life. After all what he wanted was the most basic thing (*atari mae*) [to live] and I'd have done anything if it could bring us even close to realise his desire.
>
> (Ono Yuka)

Sosuke and Yuka's experience reveals the role of hope in orienting clinical decisions at the crossing between therapeutic futility and potentially life-saving treatment. Anthropologists have shown how hope both informs medical research on untreatable diseases, and functions as a method of care in particularly wretched situations (Delvecchio Good et al. 1990; Livingstone 2012). In cases like Sosuke and Yuka's, the faith in techno-scientific breakthroughs and hope as a method of living through terminal illness were condensed in the pursuit of heroic treatment. In these circumstances, "the intense compression of outcomes, different emotional trajectories and moral meanings […] the sharp polarities, the highly charged atmosphere, and the drama and rapid momentum of transplant" drive people though hanging on uncertain chances of success (Wailoo and Livingstone 2006: 134). Such notions of hope as optimistic forecast and positive motivation shine through the stories presented so far.

On the other hand, Japanese patients and families rarely talked of hope in such a narrow sense; instead they relied widely on the more vague concept of *gambaru*. My interlocutors commonly used this term, for example, to discuss how they worked out a way to seek treatment when no option seemed available to them. *Gambaru* was also frequently used in talking of the patient's own fight with the disease. In discussing the toughness of the phases before the operation, when the family is on a race against time to raise money as the

patient rapidly deteriorates, *gambaru* was the concept of choice to describe both the parents' proactive effort and the patient's resilience. The expression "*yoku gambatta*" (literally meaning one has done her best) was used either to describe with resignation the final days of one's illness, or to congratulate for his/her recovery. Similarly, the imperative form –"*gambatte*!" –was used to wish someone good luck and encourage him/her not to give up.

A pervasive concept in the Japanese moral landscape, *gambaru* means to stick at it, to keep at it, to hold in there. As Ben-Ari notes, *gambaru* conveys an idea of persistence that includes volition, as when one makes an effort to achieve a result, but is also close to the concept of endurance (Ben-Ari 1996, 1997). It denotes a positive meaning that one has done one's best, has fulfilled all the possibilities and left nothing unattempted (Hendry 1968), and as such, it has moral value in and for itself regardless of the outcome (Kondo 1990). In this sense, as the Japanese often say, in the face of uncertain outcomes or difficulties, "one can only *gambaru*" (*gambaru shika nai*).

On one occasion during my fieldwork, I met the family of a young patient the day before they left to America, and as it later turned out a few days before the child died. Despite the fact that the long-waited moment of departure was close, the parents of the young boy were anxious and very emotional, probably, although I didn't know at the time, because of his unstable condition. As we were about to separate, I meant to wish them good luck when they anticipated me, saying they would *gambaru* in order for my wishes to be realised. Their response put what I intended to say (that I wished them all the best and I would pray for them) in a different perspective (that they would try their best and endure hard).

Although it can seem far from a European or American notion of hope, *gambaru* conveys a similar idea of a proactive and optimistic stance, which in turn upholds the clinical path of the transplant overseas and orients people's decision against adverse odds. At the same time, it also speaks of hope as resilience, and of the impossibility of giving up when there are means of indefinitely prolonging terminal conditions and treatment of last resort to bet one's chances on.

Miyazaki argues that faith doesn't emerge as a leap of belief in something that is beyond people's capacity to grasp, but as a way to one's own agency in abeyance (2000). In a similar way, it seems to me that while hope or *gambaru* drives people through as a moral imperative to leave nothing unattempted, in a way it also relieves people from the burden of the decision by putting a limit on one's capacity to understand and intervene in the course of events.

Hope, in the context of nearly hopeless clinical medical situations, is usually associated with the expectations and investments people place in scientific progress, and like the discourse of progress, it speaks of an optimistic and active stance towards the future. "Hope", writes Novas, "indicates a willingness to overcome obstacles, transcend limits and explore new horizons" (Novas 2006: 291). The analysis of Japanese patients' experience doesn't contradict this. At the same time, however, it reveals that hope itself works as a limit, of sorts, in the ways in which it orients and sustains people's decisions when 'natural' limits, in the form of the course of disease and inevitable deaths, can always be pushed one step further.

## Conclusion

The narrative above can be read in various ways. One angle from which to look at them is by pinning down the points where they intersect with each other. Ashida-san's office, Maeda-sensei's consultation room, hospital R in California, emerge as the key mediators in the networks that shape and enable people's access to care. From this perspective, this chapter provides a first glimpse into the political economy of the transplant overseas, showing how people navigated critical episodes of illness harnessing various resources around them, including medical professionals, personal connections, and formal patients' organisations, in pursuing a non-conventional treatment that was the only way to try and rescue their children (see more in Chapter 4).

As discussed at the beginning of this chapter, however, patients' narratives are not used here to reconstructed factually accurate events, but to

illustrate how people experienced them. Following the way in which interlocutors organised their narratives, I structured the chapter around key turning points: the diagnosis, the phase of uncertainty, the process of seeking help, the moment of resolution. These moments are indicative of the crucial nodes of meanings that my interlocutors put emphasis upon, and are indicative of how people make sense of critical episodes of illness and treatment. As they unfold through these seemingly fortuitous events and coincidences, the stories build up a sense of uncertainty that speak of the high risks involved and of the fact that they lie beyond one's capacity to control them. At the same time, the narratives also resolved in moments of purposefulness and decisiveness that become self-fulfilling and all encompassing (cf. Franklin 1997).

From this perspective, the stories of these *tokō ishoku* families elucidate how the medical technology compels people to choose. While they seem to unravel trough a sequence of choices, the stories show how decisions are imposed on people by the technological possibility of sustaining life past the point of non-return and by the moral imperative to leave nothing unattempted. Exacerbated by the young age of the patients, the rarity of their disease, and the unconventional nature of the only treatment available, the life histories of these families thus illustrate the moral drive that underpins the use of high-end technologies like transplant to save lives (cf. Wailoo, Livingston and Guarnaccia 2006; Maynard 2006).

Finally, as they tell about the decisions to save lives, these stories also invite us to reflect on who partakes in these choices and, in turn, in these lives. While children are the patients at the centre of these decisions, their parents emerge as the real protagonists of these stories. The narratives illustrate the role of the family in presenting decisions that are made on behalf of underage patients, and describing through Yuka's case how parents -in particular mothers- share the experience of illness with the children. The role of the family in clinical decisions has been traditionally discussed in relation to brain death to argue that the redefinition of death to allow organ procurement fail to consider that the person's significant others are invested in the individual's death (Lock 2002). These stories show that the same argument bears relevance also with regard to

the experience of transplant patients, as they illuminate the web of close relations and moral obligations in which the decision to ‘save life’ is situated.

## Coda

Aya was almost a teenager when I met her, and the Satos and the Kumanos had become good friends. After their first meeting in Osaka, the two families met again in 2009, and bonded over their involvement in the movement for the reform of the policy on organ donation (see Chapter 5).

As Natsuko said in the interview above, in the weeks before their departure, Shuichi rapidly worsened, and he died a few days after their arrival at Hospital R. When I met them, Natsuko and Keisuke had become parents to a second son, and after I left Japan, they had their first daughter.

Kaoru was almost a teenager at the time of my fieldwork. She managed to leave safely and a few days after being admitted, a suitable donor became available and she received a new heart. She overcame tough months of rehabilitation before returning to Japan, but according to her father she has almost no memory of it.

Arai-san and Nakajima-san had become good friend though their routine follow-up visits with Maeda-sensei, and Takeshi was doing very well.

Sosuke’s operation was a success. He initially showed good signs of recovering, gradually started to eat and managed to taste his first hamburger. A couple of months after the operation, he had a relapse and was readmitted to intensive care. Within a few days he further worsened to the point where there was nothing left to do, and Yuka and Kimura-sensei decided to let him go.

*THREE*

# After the Transplant

On the first day of the 2012 Transplant Games (*Ishokusha Supotsukai*), Ikuko[37] and I escorted a group of recipients from South East Asian countries who had flown to Japan to attend the event organised by the JOTNW together with the Japanese *Ishokusha* (transplant recipients) Association, the biggest patients' group in the country. It was the beginning of September, the weather was sunny, the summer heat had cooled down and the organising committee had planned a visit to the aquarium of Kamakura.

Over the following weekend, more than a hundred recipients' families gathered at the local sports centre for the Games. Many, mostly recipients' families, joined as volunteers to help out with the organisation. There were some adult patients, who apparently came every year, like 'Endo-sensei's first patient', or 'the first Japanese heart and lung recipient'. Many knew each other personally, and even when they didn't they knew each other's medical histories.

The majority of those attending were young recipients with their parents, and among them *tokō ishoku* families. Some had flown in from various parts of the country, partly sponsored by the JIA's organising committee, and they all stayed at a hotel near the sport centre. Others popped along at the end of their working day, like Hasabe-san, a man in his forties and one the 'first *tokō ishoku* recipients', who joined the social dinner to catch up with friends he rarely had the chance to see.

Natsuko also came although it was with her second son. Since she was not officially a recipient's mother she didn't stay at the hotel with other families

[37] Japanese research Ikuko Tomomatsu.

but instead helped out with the volunteers. On that occasion, she also invited the family of a potential transplant candidate to come along. The couple had just received the diagnosis for their daughter and were in the process of considering the transplant; they had contacted Natsuko through her blog to consult with her and she had seized the chance of the Games to introduce them to other recipients.

The 2012 Transplant Games I attended were the twenty-first of this foundational event of the Japanese transplant community. Together with the patients and their families, transplant surgeons, personnel from the JOTWN, and activists from patients groups like Ashida-san are brought together at the event, and donor families join the social dinner concluding the two days which thus provides a rare occasion of exchange between recipients and the donor's kin.[38] In this fashion, the Games may be the most important occasion for gathering together organ recipients and their caregivers and appear to be in many respects as instantiation of the post-operative life.

This chapter looks at recipients and families' life 'after' the transplant. Following the histories of the people I introduced in the previous chapter, I look at the experience and grief narratives of those who have lost their loved ones, and discuss how adult patients and young children alike navigate their life as transplant recipients (*ishokusha*).

Anthropological analyses of the post-transplant life have looked at how transplant recipients negotiate their expectations about treatment with the clinical complications of their condition, the financial burden of care, and the return to or pursuit of a role as fully autonomous and contributing members of society (Sharp 1995, 2006; Crowley Matoka 2005; Tomomatsu 2013). In doing so, they have provided insightful perspectives into the post-transplant life as a

38 The Transplant Games are, in fact, one of the very few occasions of exchange between recipients and donor kin. While the memorialisation of organ donors is an important part of the cultural work of promotion of this treatment, direct contact between donor families and recipients is limited and anonymous. Even when exchange is encouraged, such as with the practice of writing 'thank you letters' to the donor's families, transplant coordinators act as gatekeepers of these forms of socialisation and make sure these relationships remain anonymous (Sharp 2006). In Japan, the need to protect anonymity was a reason why encounters between donor kin and transplant patients are especially sensitive, because of the low number and high media visibility of cases of organ donation would make it easy for the donor family and the recipients to identify each other.

process of the ‘reconstruction of the self’ (Sharp 1995), focusing in particular on the reconciliation of one’s subjectivity with the incorporation of the other – represented by the organ/donor – elicited through metaphorical imageries of the gift.

Below, I take a slightly different slant on the contributions discussed above. Instead of looking at the donor-recipient’s relationship through the trope of the gift, I illustrate practices and spaces of what Rabinow (1996) termed ‘biosociality’, by which he refers to forms of sociality shaped on technological modes of intervention on one’s biology. The concept, then, captures emergent forms of sociality among people who identify themselves through a shared biological condition/medical history, and who organise around “medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene and ‘understand’ their fate” (*ibid*.: 102).

One aspect that is not usually considered when it comes to post-operative-life, however, is how people experience and understand their fate in the light of a negative outcome, the discussion on grief being most commonly confined to the experience of donor kin (Sharp 2006). It is from here, then, that I start.

## Letting Go and Pulling Back: Yuka’s Bereavement

When I first met Yuka, three years had passed since Sosuke’s death. We arranged to meet up for a tea on an afternoon in mid-December. Shinjuku was lit up with Christmas decorations and the New Year’s break was just a few days ahead. She sat down at the table where I was waiting for her, and as a first thing she pulled out of her bag the book and *manga* she had written and published about her experience. She put them on the table between us saying she had brought them for me to have, and cutting short any preliminary conversation she soon started to tell me of her nine years with Sosuke.

Yuka had a slightly pitched voice and elegant manners. She was conversational and charming. She was stubborn and could be very straightforward without ever looking pushy or nosy. She was the very image of

*yasashisa*, meaning graceful, kind and gentle; and at times she could look slightly aloof.

On our way back to the station we chatted about our plans for New Year's Eve –the habitual conversation during those weeks of the year, when most people return to their native town (*jikka*) to celebrate with their families. Yuka was planning a short trip with a friend. Her sister, she told me, was going back to their hometown, where their mother lived alone after their father had passed away, but Yuka would rather avoid the family house. New Year's Eve, she said, was a bitter moment for her and her mother; a time when the presence of those who are gone (*nakunatta hito no sonzai*) was felt particularly strongly.

Sosuke's presence was surely hardly felt. As she put it on another occasion, it was like "the presence of an absence" (*inai sonzai ga aru*). That absence shone through Yuka's every discourse and seemed to weigh heavily on her life. Yuka was always very open in sharing her feelings about his loss. She was never sentimental but neither was she reserved or shy about discussing that part of her life. Only towards the end of my fieldwork did I feel comfortable enough asking her direct questions about her life after Sosuke's death. I never wanted to touch on what I considered a delicate and painful question, and one that for a long time I saw as somehow away from my research question. But there was never an occasion when we didn't talk of how her life was without Sosuke; whether in the way she discussed her grief with other mothers, or in the allusions to some details of her everyday life that reminded of her loss, Sosuke's absence always found a way to make itself present over and over again. My impression was that lingering on it was both painful and comforting for her. She was very open in discussing her feelings and she candidly admitted that she has not yet come to terms with her loss. Four years after she had to let him go, she said, she was still trying to pull him back (*hipparu*).

During the time of my fieldwork, Yuka was living between her hometown, where she ran her business, and Tokyo, where she still had the flat near the hospital. Although she did not need that space anymore, she was not ready to move out yet. One day she brought me a bag with several DVDs of the TV news and documentaries that had been released about Sosuke's story, and told

me I could keep them as long as I returned them to her before leaving Japan because she had never watched them after Sosuke's death, but she felt one day she might want to. The Tokyo flat was the place where Yuka kept Sosuke's things, as she said she didn't feel like going through old memories by sorting them out.

The flat was a space where she could grieve. When she was feeling low she didn't want to be around people and make family and friends worry, but neither did she want to push away the sorrow. She said she often had these moments during autumn, when the anniversaries of both Sosuke's birth and death occurred, and on these occasions she stayed on her own and let the feelings that had come back so vividly, sink down.

While in Tokyo, Yuka often went back to Sosuke's hospital to visit patients she had met there. She also attended various public events about transplantation, and she was often invited by the JOTNW or organisations that worked on transplant advocacy to discuss her experience. When she was not busy with her work or with volunteering for transplantation, she hung out with friends and family and often took care of her niece. She said her sister had created for her an environment where she was needed, "because people need to feel needed."

Yuka was very well connected and well known in the field of transplantation, but she was almost disdainful of this public role, which she depicted as mostly insignificant. To make her point she often compared her experience to Natsuko's contribution to AOT's reformation (see Chapter 5). In this respect, she stressed that the legacy of Sosuke's experience was not in promoting organ donation for the sake of increasing the chances of patients to receive a transplant. Rather, it showed the importance of thinking not just about getting healthy but also about the inevitable end of life, "because in the same way as you think about how you want to live, so you should think about how you want to die." At the same time, she didn't seem to take any consolation from these activities, and every time she had to prepare a speech and select pictures to show to the audience she felt burnt out from going through the memories.

Yuka seemed to be constantly on the move, travelling around the country for the conferences, commuting between Tokyo and her hometown, and

keeping busy with her friends and family. At the same time, though, she looked stuck; unwilling, or unable to move.

Her suggestion that her bereavement might need to be as long as the life she had shared with Sosuke resonates with traditional imageries of death, and indeed time and movement are descriptive of the ways in which death is conceived in Japan. As seen, funerary and memorial rituals and imageries of the afterlife construct death as a process in time, a journey that mirrors the life of the deceased and in which the living accompany the dead (Smith 1974; Raveri 1984; Suzuki 2003). As Smith (1974) describes, alongside funerary ceremonies, memorial services constitute an essential part of the rituals of death: these are held during the 49-day mourning period, and then at established yearly intervals from the death, and the periodic anniversary of the date of death is also memorialised on a monthly and yearly basis. Through these rituals, the living escort the dead through the journey to Buddhahood and in the transition to the role of ancestor (*ibid.*). At the same time, the rituals also function to sever the ties with the deceased and to cut off the spirits of the dead from the realm of the living (Steffanson 1995; Smith 1974; Raveri 1984).

The action of 'pulling' Sosuke back seems to play with the codified imageries of death, illustrating an unresolved process of grieving. At times, this took the form of second thoughts, guilt, or regrets; at other times, manifest anger.

> We fought together throughout it (*isshoni tatakatteita*). Then why did he leave before me? We endured together (*isshoni gambatteita*), why did he leave me here by myself?
>
> (Ono Yuka)

From Yuka's experience of grief as an irreconcilable loss, death emerges as a crisis of meaning, an experience that casts into doubt the ways in which we construe our presence in the world. Sosuke's death at the early age of nine, to a rare disease, and after an initially successful intervention to save his life, is a memento of the precariousness of existence not just in its impermanence and fragility but also though the search for meaning that defines it. For Yuka, the legacy of Sosuke's death seemed to be an increased and bitter awareness that

the practices though which we ground our presence in the world are meaningful only insofar as we attribute meaning to them.

> He taught me that the small things of everyday life are not to be taken for granted. So sometimes I even feel guilty to live a normal life. Now, if I want to do something I just do it by myself, and that's it. And I know there is no way this could be different, but before we did everything together. For example, if we wanted to go somewhere it would take a lot of time [because] we had to check if there was an elevator, and I had to carry him around with the wheelchair. Now I just do it, and it's all so fast, and I can just go up and down the stairs normally. And it's so sad. Just living my everyday life is extremely sad. I had to adjust to the fact that all the small things of everyday life were not normal (*atarimae*) for us. It took time to do everything, but nonetheless we did it. Now, on the contrary, just being here and have a tea and relax…I know these things are not granted (*atarimae*). I was always constrained by time, always in a hurry, and if I just had a moment to sit down and rest it felt so good. Now the very moment I think something is good I become a little bit sad.
>
> (Ono Yuka)

## Natsuko's Closure

Natsuko's bereavement at Shuichi's death looked the farthest it could be from that of her friend Yuka. The two women themselves often compared each other's attitude toward the post-transplant life highlighting how Yuka's tenacious refusal to let the memory fade away contrasted with Natsuko's equally strong determination to move on with her life even at the cost of forgetting. Natsuko kept a blog during Shuichi's fund-raising campaign, which she continued to update even after their return to Japan. In March 2011, when the country was facing the tragedy of the tsunami that hit the North of the Japan and "don't give up" (*gambare*) became the spirit of the recovery post-disaster, Natsuko wrote about her own personal experience of loss and her attempt not to give in to it:

> Since Shuichi passed away, I have tried as hard as I could to look forward and move on. I have tried to stand firm, the more so the harder it was […] I would want to meet Shuichi with all my heart…But I know it's not going to happen, so I'd rather forget about him. (I know I can't but) I will think of him less and less until the memories almost

> disappear (*omidasu kazu ga hetteshimau kurai ni*) and I'll try hard to live my life to the fullest.

After the death of Shuichi, the Kumanos became parents to a baby boy. Natsuko said that when the baby was born they sent his pictures to the American hospital that had treated Shuichi and the doctors remarked upon his resemblance to their late patient. As the baby grew older, however, the similarities became less apparent and he developed habits and traits peculiar to him alone. During my fieldwork the baby turned two, and Natsuko pointed out that he had then passed the age his brother was when he died, disclosing how seeing her second son growing up must have given her an acute awareness of the time passing by.

Natsuko was still on maternity leave while I was in Japan, and with her baby she often attended events like the Transplant Games. The Kumanos had kept in touch with lots of the people they had met through the fund-raising and the campaign for the law's reform, and every now and then they gathered together with other recipients' families as well as people from the JOTNW. Natsuko herself organised an annual reunion for a few *tokō ishoku* families in the Tokyo area, while also trying to foster networks among mothers who had lost a child. She regarded these relationships as a way to provide mutual support and considered them all most important, given the small number of people who had gone through such an experience and the lack of official support. At the same time, she was also aware that everyone's experience is unique, and that, especially for those who had lost a loved one, the experience of seeing others who have made it can be tough.

> In part it becomes a form of support to see that some patients could become healthy. But on the other hand, those who have lost their child, and I include myself in this, well to be honest, we envy them. The process we went through was the same, wasn't it? We tried hard (*mezashita*) too. We raised the money too. We bowed our heads for help, but our child was not helped. I know there's no way to change this (*shikata ga nai*); it is what it is. Still… when you see these kids who recovered after the transplant, you think it's wonderful and you really wish them all the best and pray they can always be in good health, but as soon as you leave them you think: 'that's not what happened to my son though'. Call it jealousy, or envy; in the end it all boils down to the fact that Shu-chan couldn't make it […] It's amazing

> to see healthy children and it makes me realise how wonderful transplant medicine is and how when it works well it really produces incredible results. Still, my child could not benefit from that. So there's always this gap. I don't know about other families, but I always think of that. It's the regret about my son's life.
>
> (Kumano Natsuko)

For patients and their families, sharing their experiences with others who have gone through similar events is a way to make sense of life after the transplant (see below). There are, however, ruptures and discrepancies across people's experiences that make it difficult to share them, and so for Natsuko and other mothers it was hard to find a common sensibility with fellow patients' parents, even though she regarded all of them to be part of the same category of *tokō ishoku* families.

Distances also existed on more intimate levels. As Natsuko once told me, even after more than three years since their son's death she never talked with her husband about Shuichi's illness. She said they never discussed with each other the thoughts and memories of that period as they might well be different in some respects. The difficulties in sharing one's impressions about the experience of illness, like the distress of seeing healthy recipients, are glimpses into a process of mourning where closure seems reachable only by removing the memory of what has happened and the thoughts of what could have been. Natsuko's mourning was, in her words, an attempt to put order into her own feelings (*kanjo wo seiri suru*) by avoiding painful thoughts and memories that could drag her back into a past. And she was both resolute and torn about it.

> Everything happened in just six months, and it passed like a second. It was only after [his death] that I became able to remember my feelings, to accept how things had gone and to tell myself that there was just no way it could have been different (*shikata ga nai*). What scares me now, three or four years after, is the perception that the memory is getting thinner. There are such things, aren't there? It's not that you forget, but your memory is no longer so vivid. There are also moments when memories are almost violent, but I know that if I think of him I'll be exhausted and I'll become very sad. So I have been dealing with my life by trying to not remember, neither the good moments nor the bad ones […] It scares me when memories re-emerge and I realise I had forgotten. But if I think of it everyday, I'll get really depressed. And I don't want to cry. I don't want to have sad

> thoughts. I've had plenty already. But before, when he was here, I had to think and consider what to do. Now it's different. Now, no matter what I think, he won't come back. I did everything I could and I put all of myself into it, so I've come to the point where I can only tell my self there was no other way and that it just couldn't be helped (*shikata ga nai*). I know that's true, but as the memory of that time – that feeling of being compelled to act in a certain way, of not having a choice – is becoming more indefinite, I've also started to ask myself why. Before there was no space to think: "what if?". It was just impossible; it was all about what we had to do, as if we had no other choice. But now I found myself asking: "what if?". After I pulled myself together and the feelings settled down (*ochitsuku*), I started to wonder more and more often why. I should know better, but as the memories are fading away, feelings I had long repressed are coming back. That scares me. And on the other hand, sadness too is even stronger sometimes.
>
> (Kumano Natsuko)

## Clinical Failures: A Political Economy of Death

Despite ostensible differences, for both Natsuko and Yuka grieving was an unresolved process. Their experience resonates in many respects those described by Smith (2013) in his study of Japanese women's grief and mourning at abortion. Smith argues that the death of a child to parents, and especially mothers, remains a form of irreparable loss, and because the child is regarded as an extension of the parent's person, death becomes the loss of one's own self (*ibid*.). In Japan, the cultural ideology of motherhood as the centre of women's sense of self-worth orients affective relationships so that the woman is dependent on the child, and not the other way around (Smith 2013; cf. Befu 1971). The contemporary trend of low birth rate and the gendered division of labour also play into the social strengthening of the mother-child bond, for women devote a great part of their daily work to care of one single child. Compounding this social construction of motherhood is the role assigned in Japanese contemporary society to children, who are highly valued and cherished.[39] Particularly with the decline of the birth rate and the shift towards

[39] See Goodman on how recent demographic trends and the 'discovery' of social problems like child abuse contributed to creating this role for children (cf. Goodman 2000).

nuclear families, children are the centre of the family, and as studies on abortion and reproductive treatment show, sometimes they are subjects of affection before they are even born (Smith 2013; Ivry 2010; Kato and Sleeboom-Faulkner 2011). This strong mother-child bond, then, is expected to be both self-fulfilling for women and socially worthy, because it 'spoils' the children before they have to face the hardships of school and work life (see Allison 1991).

The discussion presented in the previous chapter shows that the experience of illness further reinforces the person's self identification with one's role as mother, for women are those who take over the care of the sick child. They move into the hospital, practically carrying out much of the work of care along with the nurses, and they almost never leave the child's bedside so that their lives become completely absorbed by their role as caregivers.

The mother-child relationship, however, is not the only factor shaping the grief of women. Indeed, anthropologists have famously shown that mothers' grief is constructed within specific political economies of death of which notions of illness are also an integral part (Scheper-Hughes 1992; Einarsdottir 2004). In the narratives Yuka and Natsuko offered of their experiences, death follows from but almost contradicts the experience of illness. For Yuka, this took the form of bitter regret for the outcome of Sosuke's fight against the disease, for Natsuko it was the unresolved questions of "what if?"

There is, of course, no answer to the question of "what if?" The disease was terminal; the decisions made were clinically wise, taken in good faith, and, most significantly, within structural conditions that made them compelling. What is more, they made them meaningful. As I have described above, and as I further illustrate in the description of the fundraising (Chapter 4), the phases before the operation are characterised by the intense promise of treatment and the proactive effort of trying to realise the transplant. These engender a sense of hope/endurance (*gambaru*) that is self-fulfilling and meaningful and gives people a way of coping with the fact that both the process and the final result are ultimately beyond their control.

Like Natsuko and Yuka, who, faced with overwhelming decisions, had no room for doubt, it seems that we too are left poorly equipped to accept deaths

like those of Sosuke and Shuichi that result from a failed attempt to save life. Sadly, though, the stories of transplant patients are often about 'bad' deaths: the death of a child for whom the fundraising was not completed quickly enough; the untimely loss of a patient who just managed to get abroad and was only one step away from the transplant; the rare complications arising after a miraculous surgery; or the story of the child suddenly dying once out of the operating theatre while her parents had been sent home by the surgeons who declared the intervention a success. Death is always the ultimate unfairness, but perhaps it is even more so when it comes as the negation of the promise of "killing death" (Bauman 1992: 129). In this sense, these fatal outcomes of heroic medical intervention stand in contrast not just to the successful experience of healthy recipients, but also to other bad deaths, like brain death.

Long (1999) for example shows that the idea of '*shikata ga nai*', which Natsuko uses to express her resignation, is drawn upon by terminal patients to make sense of death. *Shikata ga nai* or *shōganai* is a concept used frequently in Japanese, which translates as 'it cannot be helped'. It conveys a meaning opposite to hope (*gambaru*), but also to the idea of 'holding no regrets' (*kōkai shinai*) (see Chapter 2). It is not necessarily a negative resignation. For terminal patients, Long (1999) argues, it becomes a way to exert a form of control over an inevitable death. For Natsuko, quite differently, it expressed the discrepancy between treatment expectations and outcome.

Although highly controversial and disturbingly problematic, medical intervention at the end-of-life is openly construed as a matter of concern for medicine and society as a whole (Kauffman 2002, 2006). Subsumed within the category of end-of-life, states like brain death and other conditions most commonly treated in ICU and hospices confront us with the question of how to reconcile the mission of medicine to save lives, with the fact that medicine is increasingly charged with the task of managing death. Any debate on the end-of-life is obviously determined by the definition of when life is about to end (cf. Chapter 6). The non-consequential and uncertain clinical paths I explored in the previous chapter demonstrate how it is particularly difficult to trace such lines and open the door to accommodate death within the logic of a high-end curative treatment like transplant.

While the significance of death in the economy of transplantation medicine is usually discussed in relation to brain death and organ donation (Sharp 2006), the experiences of Yuka and Natsuko point to an equally important aspect of this treatment, especially in light of what is discussed in the previous chapter: how to reconcile expectations and outcomes. From this perspective, the experiences of grieving parents, while sharply different, resonate with the lives of healthy recipients.

## Takeshi: Coming Back and Following-Up

In sharp contrast to the deaths of Shuichi and Sosuke are the lives of those who made it through successfully, although sometimes it took many twists and turns, as I will show in this section.

Nakajima-san and Takeshi stayed in America for the unusually long period of ten months.[40] Shortly after the transplant, Takeshi suffered a brain haemorrhage and went into a coma from which doctors couldn't tell whether or not he would ever recover, or in what condition. He suffered severe brain damage and had to undergo a long period of rehabilitation. During this time, he experienced a second life-threatening crisis. It was the night before he was supposed to be discharged, when the boy's new heart suddenly stopped. It was a timely moment to go into cardiac arrest, Nakajima-san thought in hindsight, as the treatment promptly available at the hospital made it possible to save his life yet another time.

As soon as the child was stable enough to make the journey, Takeshi and Mariko returned to Japan. Before going home, however, they spent a further six months at Hospital J, because the boy needed close care, and Maeda-sensei took over again as Takeshi's physician. Nakajima-san remembered one of their first sessions with the physician. The brain damage had left Takeshi almost paralysed in one arm, but other than that he had not suffered permanent consequences or cognitive impairments because his young brain was

[40] Compared to the usual two to three months recipients spend overseas before returning home where they can rely on insurance coverage for their after care.

adaptable enough to compensate for the severe damage. As Maeda-san checked his patient's records from the overseas hospital, he could hardly match the picture of the CT scan, half black because of the vast area of tissues that had been damaged, with the image of the healthy boy in front of him. "You really came back to life (*seikan*)!" He apparently exclaimed.

Years later, I joined Mariko and Takeshi on the occasion of another appointment with Maeda-sensei. Once every two to four weeks, Nakajima-san drove to Tokyo from their hometown, a couple of hours from the capital, for Takeshi's follow-up visit. That day, their appointment was scheduled early in the morning. When I arrived at Hospital J, Nakajima-san and Takeshi had just finished and were waiting for other patients to head out to lunch together. Since we had some time to kill, we seized the chance to pop down to the paediatric unit a couple of floor below to visit Mai, another patient of Maeda-sensei who at the time had just come back from the States.[41] Nakajima-san got to know Mai and her mother after the girl was hospitalised at Maeda-sensei's unit, and this was the first time they had met following the operation.

When we got to the girl's room, the nurses at the reception told us that Mai was momentarily away for treatment, so we sat down in one of the waiting rooms. Shortly after, Ai showed up. Taking advantage of Mai's clinical routine, she had left the hospital to quickly grab some food at the convenience store down the road. Without much ceremony, Ai devoured her ready meal raising her head from the bentō box only to tell Nakajima-san of how tired she was. The operation had gone well, but Mai had suffered some complications and still needed to be at the hospital. She was not in danger for her life, but she was temporarily on artificial feeding for complications from the surgery. Ai could hardly find a moment to have a meal too now that girl couldn't eat, and so she squeezed out of the room when she could to go to the closest store or, at the very worst, to the toilets down the corridor where she had hidden a box of biscuits. Ai had hoped that once back from the States she could go home; now she was looking forward to being discharged in time for New Year's Eve.

Ai was visibly pleased to have someone to talk with, but she was short of time to chat and had to rush to shower before Mai's therapy was over.

[41] Her story is told in Chapter 4.

Nakajima-san offered to look after the girl so that she could take her time. Shortly after she returned, Yosuke called and Mariko, Takeshi and I left to have lunch.

Yosuke was a young man in his twenties, who had also received a heart transplant in the U.S.A. as a child. Nakajima-san had already introduced us at the Transplant Games where they were hanging out with a small group of other recipients of different ages from Hospital J. Among them Takeshi, who was not yet even ten, very clearly liked to hang around with Yosuke and another young man who was also in his early twenties, teasing them, wrestling and playing with the older boys.

Takeshi was in good health, quite a handful to tell the truth, and had never had major problems after the transplant. In the family restaurant we headed to after the hospital visit, Takeshi and Yosuke were talking animatedly in one corner as Nakajima-san and I chatted over lunch. As the mother of a transplant recipient, she said she was aware that Takeshi might have problems with his health, and then added under her breath that I shouldn't mention anything to him.

For parents of young recipients, school is the place where these sort of concerns are first confronted. Returning to life after the transplant generally means going back to school or work, and indeed the very efficacy of transplantation is measured up against the ideal of *shakai fukki* (see Chapter 2). For young recipients this return to society primarily means going back to school and making friends with other kids. One of the worries recipients' parents most commonly voiced was bullying (*ijime*), a widespread phenomenon in Japan that is related to the conformity and competitiveness of the school system[42]. Even before the operation, Nakajima-san had had trouble with Takeshi's school. Once she was asked to take the boy home if he needed the toilet because he could not use the ones provided. Even though after the transplant Takeshi was doing fine, she still had to be with him during school trips (and pay her own way to do so) because no one would take the responsibility of having a disabled child with the group.

[42] See Yoneyama (1999).

In Japan, transplant recipients are recognised as disabled (*shōgaisha*) and are entitled to social welfare benefits and financial assistance for the expensive post-operative treatment. The system spares them in part the economic hardships of care that Sharp documented as bringing many American patients to the brink of bankruptcy, making clinical compliance a short-sighted fantasy (2006, 1999; Gordon et al. 2008)[43]. On the other hand, however, 'coming back to life' only to be disabled is hardly what anyone might hope, especially in a highly conformist society where the label of disability is still widely accompanied by prejudice. Nakamura illustrates attitudes towards disability (in her case, deafness) in Japan, describing the pressure to conform at school, the assumption that differently-abled people lack the capacity of being independent and contributing members of society, and the prejudice against marrying disabled people (especially women) for fear that children would inherit their 'impure blood' (2006). Disability, as Nakamura shows, is traditionally associated with impurity (*kegare*, see Chapter 1), and people suffering from it were therefore ostracised from society in a similar way to the *burakumin*, Japan's largest minority group that has been long discriminated against because it is associated with polluting occupations such as undertakers, tanners and others (Amos 2011).

Fearing social stigma, transplant patients of an older generation reported concerns that their status as disabled would compromise their chances of finding a job, relegating them to occupations within the disabled quota; or that their state of health might affect their chances of finding partners and building a family (JTRO 1994). For healthy recipients, long-term survival is characterised by the risk of rejection and life-long medication with its attendant side effects, so that Ikels writes that becoming a recipient means in fact to "exchange one illness with another" (2013: 93). The condition of being an *ishokusha* therefore elicits specific strategies of re-moulding patienthood into one's social persona (see Sharp 1995, 2006; Tomomatsu 2013). In this sense, the positive acceptance of *shakai fukki*, as promoted by patients' groups, can be seen as a

[43] In fact, insurance coverage doesn't include the entire costs of treatment, let alone the expenses patients' families incur in attending follow-up visits at medical centres often located far away from when they live, so almost everyone complained of the financial burden of the after-care.

crucial part of the cultural work of validating the efficacy of transplantation medicine.

After their return from the States, Takeshi took part in the school sports day, a highlight of the Japanese school year, and competed in a race with his classmates. Naakajima-san told me that after the game the school head approached her and commented on Takeshi's running style, defining it as unpleasant to see (because of his immobile arm). "He never accepted disabled children," said Nakajima-san, "because he thinks they are just a burden and that they contribute nothing." On the other hand, she added, the parents on the bleachers cheered Takeshi whole-heartedly regardless of his physical problem, or maybe, one could speculate, because of it, since they probably knew very well his story through the fundraising campaign.

Excessive attention is as much a concern as negative prejudice for the families who travelled overseas. The fund-raising forces people to go public about their disease, which is the reason why Maeda-sensei often warns his patients to conduct low-profile campaigns and limit media exposure. For Nakajima-san, this led to quite extreme consequences, when she returned to her hometown and noticed that Takeshi was stalked by a woman who, it turned out, had become obsessed with the child, following his story in the media.

Although similar cases are rare, the fund-raising arguably puts young patients under intense public scrutiny. It attracts overwhelming attention, to the point of turning children into subjects of compassion if not pity, and if this visibility works well to prompt fast donations during the campaign, it can leave people exposed once the whole experience is over and they have to return to everyday life (cf. Chapter 4). It also requires families to publicly disclose information and details about the patient's disease, which most people described as being highly unpleasant and uncomfortable because disease, like disability, is associated with physical and therefore social difference (Ohnuki-Tierney 1994). From this perspective, Tomomatsu shows how Japanese recipients, especially of an older generation, internalise social stigma about their condition as well as their medical history (2013). Nakajima-san, for example, expressed concern that even though Takeshi was in good health, the simple fact of having done the fund-raising and having received a transplant

could make him vulnerable to unnecessary pressure: “Like when people ask: ‘but can you do this?’ or ‘are you able to do that?’” In this sense, the life after the transplant at risk of nullifying the very therapeutic effect of ‘returning to a normal life’.

When I met Nakajima-san and Takeshi more than five years had passed since the operation. Things were going well and their lives had settled again. The journey overseas, the surgery and the following complications seemed a dim memory, probably a blurred one for Takeshi who was very young at that point. Transplantation, however, was still very much part of their life, in the form of occasional events like the Transplant Games, as well as through the monthly check-ups with Maeda-sensei and the daily routine of medication.

The therapeutic experience of transplantation is often construed through the trope of ‘returning to life’. As in a comment Maeda-sensei reportedly made about Takeshi's recovery, the imagery can convey the powerful idea of an almost miraculous technology that “alone can make the impossible achievable” (Awa 2009: 96; cf. Sharp 2006). Unsurprisingly, post-transplant life is never talked about in terms of survival rates once one starts living it (such statistics being mentioned only in relation to treatment choice), and is rather envisioned in terms of a return to a life that is both physically and socially fulfilling. Cast in this way, transplantation becomes almost a rite of passage from illness to health (Crowley-Matoka 2005). The therapeutic experience is fixed to the time of the operation and to the period immediately preceding it, and these phases are emphatically described as momentous, riddled with uncertainties and emotionally overwhelming. As with the tragic deaths discussed, the recoveries are often extraordinary, and symbolically represent the conclusion of the phase of transition before life can return to what it was, or is supposed to be, without the disease.

The experiences of Nakajima-san and Takeshi thus show that the therapeutic experience continues into one’s life after surgery. Miracles are made up of precarious ordinariness, and ‘returning to life’ involves the continuous labour of following-up. As with Takehsi’s brain after the haemorrhage, life readapts to a new state of normality; one, however, where

normality is always endangered by clinical complications as well as the awareness of one's history and condition.

## The Aftercare

Clinical follow-ups, like those Takeshi attends every few weeks at Hospital J, are routine for transplant recipients. After the transplant, recipients are dependent on a complex regime of medication to keep rejection under control, and have to comply with regular monitoring to track the effects of drug therapy and to adjust it accordingly. For this specialised post-operative care, people continue to refer to the medical centre where they received the operation. Since transplantation is an elective and high-end treatment, and a higher volume of patients often translate into better clinical outcomes, only selected hospitals run transplant programmes, and these become places recipients concentrate around. Those who travelled overseas for treatment usually remain under the care of the physician who arranged for the operation abroad, meaning that many refer for care to hospitals located in cities quite far away from where they live, like the Satos who commuted monthly between Tokyo and Osaka for Aya's visits.

As the number of patients (at least those treated abroad) is quite limited, these periodical check-ups are often scheduled on the same day and become an occasion for recipients and their kin to meet up with friends and acquaintances they would rarely get the chance to see otherwise. Month after month, newcomers join as well. Some are in the process of preliminary consultations, others are waiting to leave and still others have just begun to attend the hospital for their aftercare, if the operation went well. In some cases, it is the physician himself who introduces former recipients to new candidates, in order to facilitate the exchange of information. Other times, even though the doctor might want to protect their patients' privacy, it is enough to see an unfamiliar face in the waiting room to guess the identity and story of the new patient, for both fund-raising campaigns to go abroad and the even rarer

operations performed in Japan are usually reported in the news and can be easily kept track of.

Directly or through hearsay, patients get to know and follow-up each other, and friendships are forged around these periodical meetings. Recipients and their caregivers would take advantage of the appointment with the physician to visit any hospitalised friends, and sometimes organised the journey to the hospital together. They would chat in the waiting room, keeping updated with each other's lives and asking abut those who might have missed a few visits to make sure they are doing well. They catch up with those returning from abroad during the first critical months after the intervention, often having followed their experience through the pre-operative hospitalisation and the fundraising.

In the long run, and in the absence of professional support from figures like social workers or transplant coordinators (these last dealing only with recipients treated in Japan), socialisation among fellow patients becomes a form of mutual help, both emotional and practical. In their everyday life interactions, recipients and their families can be uncomfortable and unwilling to disclose too much about their condition, especially if it is problematic. On the other hand, the sense of gratitude (*kansha*) for the life saving gift of an organ and for the support received through the fund-raising can translate into a feeling of being disenfranchised from openly voicing concerns about life after the operation[44].

In contrast, the common routine of care and the occasional meetings outside of the hospital, like the gatherings Natsuko was keen to organise, bring recipients and their families in touch with people who already know about their condition and have gone through similar experiences. A shared medical history thus becomes the centre around which solidarity and interpersonal bonding are built (cf. Radin 2005). For some people, these interactions are the means through which to organise their experience of illness and treatment, while for others retreating from such exchanges can be a way to achieve a sense of having overcome the disease. In this way, patients' socialisation becomes a

[44] Fox and Swazey (1978) and Sharp (2006) similarly note how the metaphor of 'the gift of life' robs people of the possibility of voicing complaints about the post-operative problems and can result in a sense of guilt towards the donor in case of rejection or health complications.

way to mask or express anxieties about the illness experience, whatever its epilogue.

> Whether one's child has died or recovered successfully, we all went overseas for the transplant; we all did the fund-raising, and that's a really extreme experience. We're just a few people in Japan [who have gone through this]. For some, I think, it's hard to go public about such an experience: some might have gone through a lot of trouble to raise the money, and for all the families who received support and comprehension, there are also those who had problems. In our case, we had the support of our families and a lot of people around us. So in a way it's hard to complain when so many people have helped you; you feel like you can only be grateful. That's why every now and then the few of us who share this experience get together. It makes you feel like everyone has endured a lot. It feels good for example to meet for the festivities throughout the year: during the year there might have been bad things, or maybe there was nothing bad at all, but when we get together I feel somehow relieved. I feel that we all endured together and we're still together. It kind of gives me the strength to do my best also in the future.
>
> (Kumano Natsuko)

## The Networks of Transplant Recipients and their Caregivers

Along with fellow recipients, patients also develop a close relationship with their doctor (*sensei*), one of both confidentiality and dependence (see Tomomatsu 2013: 135). The transplant overseas builds an intense bond with the physician, further reinforced through the regular follow-up care. Recipients and their caregivers often identify themselves as patients of one doctor (*sensei no kanja*) or members of the group of another (*sensei no gumi*). Physicians become familiar figures: sometimes they hang out with patients after their visits or on the occasion of educational events about transplantation, and they often remain in touch also with those whose children couldn't make it, like Kumano-san. At the same time, they act as gatekeepers of patients' socialisation. They encourage their participation in events like the Transplant Games, or limit their interactions so as to protect their privacy, taking care so that those who are going through hard times or who are facing a difficult recovery don't feel forced to be around healthy recipients.

The networks of recipients, their caregivers and medical professionals play a crucial role in shaping the experience of treatment. Seeking advice from patients and their families enables potential candidates, like the young couple who met Kumano-san at the Transplant Games, to envision life after the transplant in ways relevant to formulating their choice (see also Chapter 2). But the need for mutual support and peer exchange among fellow patients doesn't end with the operation. Sharing information, concerns and advice is a way to negotiate the small and large issues of life after the operation for which one shouldn't bother to contact the physician. As with Nakajima-san's problems with Takeshi's school, most of these issues are in fact better discussed among peers rather than with a medical expert, for they escape clinical concern and rather have to do with questions of how to balance care with the commitments and leisure of everyday life, how to cope with going back to school or work, or how to be responsible for the after-care on behalf of underage patients.

If clinical appointments and informal gatherings are the commonest occasions for recipients and their families to meet up, patients' organisations and even individual physicians regularly run public events where patients' participation is key. Both Kitana-sensei and Maeda-sensei, for example, are famous for their annual public lectures, like the one Arai-san attended when he was considering listing his daughter for the transplant. These seminars, at least the ones I took part in, host talks by medical doctors, researchers, and transplant coordinators, as well as the testimonies of 'their' patients, who sometimes travel from distant provinces to attend. At Maeda-sensei's seminar, for example, a first panel including talks by various professionals in the field of transplantation was followed by a session entirely dedicated to recipients and their kin. Patients took turns on the stage to briefly talk about their experiences (usually pointing out what type of transplant they received and when). After the presentations, chairs were pushed against the walls to clear space for a small buffet, and the last hours of the day were spent chatting with fellow recipients and a few members of the medical staff from Hospital J, the cardiac unit.

Bringing together recipients' families, medical experts, volunteers from associations like NIT Japan, and occasionally donor kin, these events foster the consolidation of what is called the 'transplant community' (*komyunitii*). The idea

of a transplant community is not peculiar to Japan, and one can rather guess the inspiration comes from overseas. These forms of socialisation are intrinsically linked with the nature of the treatment, for patients are dependent on and tied to the medical world for the rest of their lives after the operation, if nothing but for follow-up care (Siminoff and Chillag 1999). Yet the degree to which people might get involved, and the extent to which they feel able to share their experiences obviously vary. For each person who attends events like the Transplant Games, there are others who avoid these situations because they choose to prioritise activities unrelated to transplantation; still others seemed to take part only in the seminars organised by the doctor they directly feel linked to.

More than belonging to a community, then, recipients are part of what Nakajima-san described as horizontal 'networks' (*nettowaku*), as opposed to the presumably vertical relationship between patients and doctors. Patients' position within the world of transplantation, with both its institutional organisations and its shared imageries and rhetoric, is not a fixed one. They move along these networks pulling strategically on their connections as they work around and take advantage of their position as recipients of medical care. The modes and dynamics of these interactions change, so that comparing for example the experiences of the first generation of patients with those of the families of young children it appears how the rise in the number of patients and the easier accessibility of information on-line have made formal membership in patients' associations less relevant than in the past, where patients' groups acted like the key centre for guidance on treatment and practical support after surgery (see also Chapter 5).

These forms of sociality are therefore crucial for recipients in order to make sense of their life after the transplant. On the other hand, however, the relationship is mutual and patients are indeed essential – one could argue even instrumental (cf. Sharp 2006; cf. Ben-David 2005) – in the clinical success of transplantation. The Transplant Games are a case in point. The event is a performance of health and fitness, meant to convey the greatness of transplantation (*ishoku no subarashisa wo tsutaeru*). Through these kinds of practices and rhetoric, healthy recipients become the living testimonies for the

efficacy of transplantation, a role they often take consciously upon themselves out of gratitude (Siminoff and Chillag 1999)[45]. While sharing one's personal experience is a way to make sense of it, life histories are also traded, in the sense that they collected and celebrated as evidence of the miracle of transplantation medicine. From this perspective, recipients do not simply rely on professionals' expertise and friends' tips; their lives become a form of knowledge in and of themselves, measured in survival rates, shared as advice, and memorialised in the form of educational campaigns on organ donation.[46]

Writing about America, Sharp (1995, cf. 2006) has amply discussed the relationship between recipients, donors, and the medical establishment in the field of transplant in relation to what she calls the "ideological underpinnings of transplantation". Sharp notes, for example, that the all but rare complications of long-term survival are carefully silenced in recipients' public accounts of the post-operative life, and shows how patients' real experiences often appear in stark contrast to the rhetoric of health which is at the core of the transplant ideology. Sharp uses as an example the comparison between HIV/AIDS and transplantation, which is strongly discouraged despite the clinical similarities, and argues that the emphasis on health that informs the official and public representation of the post-transplant life can in fact deprive patients of any recognition of their distress. In this sense, Sharp argues, recipients' suffering, like donor kin's grief, is sanitised so as not to undermine the task of donation and the social worth of the transplantation enterprise (2006). Giving voice to American recipients' experiences, Ben-David even argues that patients are left at the mercy of doctors' false promises of immortality, which are ultimately driven by the professional ambition of the medical entourage more than by the realistic commitment to enhance patient's health (2005).

These arguments show how the post-transplant life of recipients (and donor kin) is tightly interwoven with the question of transplantation efficacy in the public arena. This is particularly true in Japan, where the technology of

---

[45] One example is the poster Sato-san proposed with the JOTNW, which would feature pictures of various transplant recipients and was to be used in promotional campaigns to encourage organ donation to show how people can get healthy after the treatment.

[46] The JOTNW, for example, publishes a monthly newsletter called Think Transplant with recipients' stories.

transplantation has been for a long time vehemently contested. From this perspective, the experience of Japanese patients complicates the critique advanced by North American anthropologists. In Japan, patients strategically harness their connections with the medical establishment in order to pursue care (Chapter 2), and while physicians act in many ways as the gatekeepers of patients' socialisation by virtue of their medical authority, recipients and their families also seem to cultivate and rely upon informal networks of mutual solidarity. Far from being victims of unscrupulously ambitions doctors or passive recipients of care, Japanese patients have been actively engaged in the creation of the local transplant community and can be said to have played a crucial role not only in public promotion but in the legal regulation of this medical technology (Chapter 5). In the same way, they are also active subjects in the way they negotiate their personal and social experience as transplant patients.

## 'Transplanted Persons': Overcoming and Performing Patienthood

Hasabe-san was in his forties and belonged to the first generation of Japanese transplant recipients. He received his heart transplant in the early 1990s in America, when in Japan brain dead organ donation was not permitted. At the time of the operation, Hasabe-san was in his early twenties; he had been diagnosed with DCM a few years before, and since then had been in a routine of frequent hospitalisations. His condition degenerated into heart failure and without the artificial support that was now available, his physician gave him a prognosis of no longer than one year. It was his Japanese doctor, Hasabe-san said, who proposed the option of the transplant.

At the time, Hasabe-san told me, transplantation was a matter of great public interest in Japan because of the debate over the law that would authorise organ procurement from brain dead patients. In discussing the decision process and the consultation with the medical staff, Hasabe-san emphasised the negative imageries that surrounded transplantation at the time and that weighed

heavily on his choice: besides the notorious contestation of the ethics of organ procurement, transplantation was commonly regarded as an unsafe procedure, and the life after it was depicted as fraught with clinical complications and similar to the badly stigmatised condition of HIV/AIDS. He also thought that one of the most evident differences in the staff that assisted him in America was that the Japanese coordinator couldn't provide more than clinical information and lacked practical knowledge about recipients' real lives after the operation, for there were almost no heart recipients in the country at the time, and this shaped the way in which he approached treatment as a candidate.

The talks with the Japanese coordinator, however, enabled him to overcome his guilt and the fear of negative judgment by re-considering organ donation in a positive light, not as a sacrifice but as a gift out of willingness to help others. His story resonates with the point anthropologists have made, arguing that metaphorical images of organ donation frame the use of the human body as a therapeutic resource contributing to the acceptance of organ transplant by both recipients and the general public (Hogle 1999; Healy 2006; Joralemon 1995). Sharp, for example, analyses the trope of the gift and the attending personification of the organ to discuss the recipients' reconstruction of selfhood in the post-transplant life (1994). Yamazaki describes similar dynamics in the way Japanese patients make sense of the therapeutic experience by imagining a relationship with the person of the donor as embodied in the organ (2009). Sasaki (2008) argues that the image of the 'relay of life' apparently took over in Japan as an alternative to the 'gift of life' because it offered a culturally more attuned way of framing anonymous donation in a society where gift exchange is deeply embedded in networks of reciprocity (cf. Rupp 2003). Tomomatsu describes that through the metaphor of the 'relay of life' Japanese recipients ascribe life to the organ and thus overcome the guilt towards the sacrifice of the donor by imagining donation as an act through which the donor lives on (2013: 169).

Hasabe-san too relied on this metaphor, but he elaborated on it with his own imagery about his relationship with the donor.

> Transplant is often called the relay of life (*inochi no rirei*), but I don't think that's the case. To me it's more like a three-legged race (*ninin sankyaku*) […] It's like I'm walking with my donor, not just the organ but the donor. It's not so much a mental image; it's [how I think of it]. In the end it's my donor who is sustaining me, because without the heart I wouldn't be alive. I mean, body parts are body parts, but it's like through them the donor and I have become one. And to me that's like walking side by side with someone else. But if [the transplant] was like a relay race one would be able to move freely. In a three-legged race instead you often stumble and fall. As in a three-legged race, there are those who cannot walk and can only toddle, those whose rhythm doesn't match, those who fall and those who can run really fast. If it were a relay, getting the baton would be the end of the donor's [presence]. Instead for me, even after all this time, this heart is still not mine. It's my donor's.
>
> (Hasabe-san)

Alongside the issues of death and body ownership, the complex work of imagining the relationship with the donor becomes, in the words of Hasabe-san, a way to make sense of the responsibility and uncertainty that characterise the condition of being an organ recipient.

More than twenty years after he received the new heart, and after a sequence of crises and more stable periods, Hasabe-san was listed for a second transplant in Japan when I met him.

> One month after the transplant I suffered a severe rejection crisis, and then again half a year later [I went into rejection another time]. My condition was, how can I say, quite poor (*omowashikunai*), so at the beginning I was very careful to take care of my health (*taichō no kanri*). But as my situation improved I kind of let myself go. Almost ten years after the transplant I started to feel I wanted to do something with my life. I found a job [as *salaryman*], and as I started to work, work became the most important thing, more important than the donor. My employers and colleagues knew about my condition and I had informed them that there were things that could be physically too hard for me. Still, I didn't want to be spoiled […] For almost ten years since my transplant, I had put in a lot of effort to help promote and develop transplantation medicine (*ishoku iryō no keihatsu to suishin*) [by taking part in advocacy initiatives by transplant recipients]. I devoted a lot of energy to that, on top of having to take care of my physical condition (*jibun no taichō kanri*). So, in a way, my life after the transplant was about nothing else but the transplant (*ishoku igo no seikatsu ha ishoku shika nai to iu seikatsu shiteita*). Then at one point I started to question that: what was the worth of all the efforts spent to get healthy again (*sekkaku*

> *genki to natta nanda ka*)? One reason why I got to thinking about that was that, right at that time, I lost my mother to a disease. I [found myself alone and] had to take care of my life. I had to find a job. I wanted to build an independent life (*jiritsu seikatsu taterō*) and do well on my work (*shigoto ni gambaru*). But eventually it took over, or maybe I wasn't able to take care of everything. Anyway, once I started working I ended up prioritising that [aspect of my life] and wasn't able to manage well enough [with my medical care]. That's something I'm struggling with now (*hansei suru*). I feel like I forgot about my donor. If you feel grateful toward the donor you have to adjust your life, even if busy, so that you don't forget about medication and if you're overworked you can take time off, and so on. I didn't do it. It was very appealing to be healthy again after having done so much to get there, [and I wanted to make the most of it]. I wanted to prove I could do everything normal people can do (*futsū no hito no onaji yōni dekirundatte*). But that was a mistake.
>
> (Hasabe-san)

Hasabe-san's narration brings to the fore the tensions at the core of the post-transplant life. His experience illustrates how completely taking up the identity of a transplant recipient can become an obstacle to developing a socially and personally fulfilling life, while on the other hand the attempt to engage in a supposedly normal lifestyle got in the way of caring about his condition. Crowley Matoka finds very similar dynamics in the experience of Mexican organ recipients, in this case further aggravated by sharply unequal access to care, and describes the condition of being a transplant recipient as one of "persistent patienthood" (2005: 828; 827).

For transplant recipients, the negotiation of patienthood indeed takes the form of the refutation of the role of patient.

> Even now there are still some doctors who would use the expression transplant patients (*kanja*). But transplant patients are not patients. We don't need to think of ourselves as patients (*kanja ishiki de nakutemo ii*). Obviously we have to take care of ourselves (*jikō kanri*), but we're not patients. We can do everything that normally-abled people (*kenjōsha*) do. So I think that to live as a transplanted person (*ishokusha*) means to live as a healthy, normal person (*kenjōsha*).
>
> (Nakamichi-san)

The very word *ishokusha*[47] was an invention of Nakamichi-san, the former leader of the Japan Ishokusha Association and probably the most famous transplant advocate in Japan (see Chapter 5). The negation of patienthood, or in Nakamichi-san's terms the act of "getting rid of one's awareness of being a patient" (*kanja ishiki wo suteru*)[48] is a refutation of a condition associated not just with physical and social impairment. The efficacy of transplant, therefore, is gauged against the expectations of leading a life that conforms with certain social expectations. Fitting in at school, finding a good job, and, especially for women, getting married and becoming a parent are all widely shared, and almost hegemonic assumptions of what a 'normal' life is in Japan. Working hard and being committed is particularly praised in Japan (Gordon 1996) and, as the story of Hasabe-san illustrates, it is in this public arena that the therapeutic efficacy of transplant is gauged. In this sense, similar to what Traphagan (2000) writes about *boke* (aging), *ishokusha* can be viewed as a moral concept tied to the social responsibility to be an active and contributing member of society by taking care of one's health and avoiding becoming a burden on others (2000). Health, it appears, is defined not by the absence of disease but as a "margin of tolerance for the inconsistencies of the environment" (Canguilhem 1991: 197).

Adding to this, Hasabe-san's life as a long-term recipient shows that the question of how to negotiate the therapeutic efficacy of transplantation is not confined to the political agenda of patients' advocacy, as how to live as a transplanted person remains a quandary for any recipient and her caregivers. From this perspective, his life after the transplant well illustrates that if health is a 'margin of tolerance', it is one that has to be constantly conquered and policed. Repeated over and again is the idea that transplant recipients have to exert control over their life (*jikō kanri*) because their very life depends on compliance with their after care. In a book published by Nakamichi-san's organisation, and collecting the scripts of one of their meetings, the idea of 'self-management' (*jikō kanri*) is discussed in terms of "responsibility towards life itself" (*inochi ni taisuru sekinin*), meaning the biological life of the organ, and

[47] The word, in fact, is used interchangeably with the terms 'recipients' (*resipiento*) taken from the English equivalent, and 'patient' (*kanja*), employed when talking of relationships with the medical staff.
[48] Personal communication.

therefore of the donor and the recipient alike (JTRO 1994). While health is imagined as the overcoming of the consciousness about one's condition, care brings the body back to self-awareness as a subject of conscious, even obligatory, intervention. In this way, to define the precariousness of health is not its opposite (disease or clinical complications), but its necessary prerequisite: care.

Anthropologists, as I have argued, usually deploy the trope of the gift to discuss the post-operative life, analysing clinical compliance in terms of gratitude towards the donor, and discussing both the positive and "ideological" meanings of the metaphor of the gift in enabling recipients to construe the incorporation of a stranger's organ and/or disenfranchising them from the possibility of voicing their concerns and claims. While these analyses are insightful in many respects, the concepts of awareness as a recipient (*kanja ishiki*) and responsibility towards life (*inochi ni taisuru sekinin*), which I borrowed from the narratives of the Japanese recipients themselves, offer a more challenging angle of analysis, for they bring to the fore the shifting meanings of embodiment instead of focusing on symbolic representation. In this way, they open some new space to look at transplantation efficacy in relation to our conceptual understanding of the body as a subject of therapeutic intervention.

## Aya's Care

Over the summer, Kanemaru-san informed me that Endo-sensei and the Japanese *Ishokusha* Association were organising a two-day camp for young organ recipients and their families. Knowing they were recruiting staff, I applied as a volunteer, specifying my role as a researcher and my connections with some of the families under the care of Endo-sensei.

The reply was immediate, and from Endo-sensei himself. He let me know that the deadline for applications was closed but said they could still make an exception, considering I had been introduced by Kanemaru-san. He also added I would have to organise my journey and stay by myself, but didn't provide any information about where the other attendants/volunteers were booked, neither

did he direct me to the organising committee for more details. My guess that I was allowed at the camp as an unwelcomed presence only to not disappoint Kanemaru-san was confirmed by Endo-sensei's prohibiting me from asking the young recipients and their families any questions about their experience of the transplant. Considering that it was an event about transplantation, the request was the closest we could get to me not attending at all, and so I didn't.

However annoyed I felt at the time, my failure to attend the camp got me thinking about the dynamics of patients' socialisation and how, as Natsuko described above, there are gaps and distances across which experiences cannot be shared. Even just reminding people that there was such a thing as a transplant experience, and that it was something peculiar to them, could be a source of distress for the young recipients and their families. As Endo-sensei pointed out, it would in fact spoil the spirit of a camp that aimed at providing an escape from the worries people already faced in everyday life as an organ recipient. In a way, the very idea of the camp was that being cared for should also include being allowed not to care.

I later heard about the camp from Sato-san, who took part with her husband and Aya. While the girl was busy with the activities organised for the children, the Satos sat in on a few talks for recipients' kin. Sayaka told me she particularly enjoyed the seminars where older patients, who like her daughter had received the transplant overseas at a young age, discussed their experience of attending school, finding employment and becoming adults as organ recipients. The questions discussed at the camp were not just matters for an occasional chat but frequently debated issues in the Satos' household.

Her husband, Sayaka told me, would have liked Aya to become actively involved in promoting organ donation. Sato Keisuke was particularly passionate about reading up on transplantation and frequently attended public events concerning it, from study groups at the MHLW, to other patients' fundraising campaigns. He used to bring his daughter over when he could, and he wanted her to be knowledgeable about the treatment and actively involved in transplant advocacy. Sayaka, on the other hand, was more worried that the girl's condition didn't keep her from focusing on her studies and enjoying time with her friends.

Aya was almost a teenager when I met her, and it was now up to her to decide whether or not she wanted to participate in the summer camp or the Transplant Games. But growing older also meant that the Satos could reveal aspects of her medical history that they couldn't discuss with her before, such as the fact that organs are procured from dead patients. Making Aya aware of her condition was also of importance for her care, for the girl was increasingly responsible for it. Since both Sayaka and Keisuke worked full time and Aya was often on her own at school or out with friends, she had to take her medication by herself during the day. Educating Aya about her condition and the attention it required was thus part of the necessary care that the post-transplant life demands, as well as a way to allow her to be more independent. Sayaka judged that in these respects parents can easily become overprotective, while for their part, they didn't put limitations on Aya's physical activity or her social life.

Behind their attitude, Sayaka pointed out, was the fact it was odd to educate Aya to pay special attention to her health because she had no understanding of her physical condition being any different than that of friends. Aya recovered brilliantly after the operation, and was the typical example of the healthy recipients whose recovery illustrates the greatness of transplant. The Satos knew that Aya was lucky to have enjoyed such a good recovery, but on the other hand she didn't care, as her mother pointed out.

> What's quite typical about my daughter is that she was never aware of her illness. She was told about it, but she's never been physically constricted or anything like that. She was transplanted at an early stage [of the disease], and while in a very good physical condition, so she was leading a really normal life before the operation. This also helped her recover very well: she was in hospital for only six days after the transplant. In fact, she has very little experience of hospitals at all […] While we were in Japan there was no treatment, no machine, no drugs that could help her [so she was never hospitalised]. She basically was at the hospital only for the surgery, and now for the follow-ups […] She doesn't think she was ill […] She's always in trouble when people and journalists [at events like the Transplant Games] ask her things such as:
> "So how did the transplant change your life? Are you happy now that you're healthy again?"
> I guess they'd like her to reply: "Oh, I'm so happy I can run now!"
> But the truth is she could run even before. So in the end she just says she's got no idea. (Sato Sayaka)

Aya might have no experience of her condition as being problematic, but her health was regularly checked and discussed between Endo-sensei and her parents. During a meeting when we talked about the summer camp, for example, Sayaka told me they had recently been to Osaka for their monthly visit and that tests had found slight variations in Aya's values that could require a change in the dosage of her immunosuppressant drugs.

As Sayaka reasoned, health is the silence of the body and the absence of an awareness of one's physical condition (Leder 1990; Murphy 2001). Illness, as pain and impairment, breaks this condition and brings the body back to self-awareness in problematic ways, but pathological conditions are not the only modes in which the body raises to consciousness. As Leder argues, clinical tests make invisible processes in the body visible, interpreting them in relation to normative standards of health, while drugs enable us to indirectly control bodily functions that are otherwise beyond wilful intervention and even conscious apprehension (1990). In this sense, care itself becomes a "situation of non-obviousness in which some aspects of the network of tools we are engaged in using is brought forth to visibility" (Martin 1990: 422).

Martin writes about the imageries used in popular and scientific accounts in the field of immunology. It is obviously no surprise, considering the emphasis on health that defines life after the transplant, that immunosuppression remains invisible in the way transplant is conceived of as a therapeutic experience. Immunosuppression is exactly the opposite of restoring or boosting health from the outside, it is a process of "dying from within" (1994). Through immunosuppression, life itself gets in the treatment's way and the cure generates the pathology through the process of keeping life stable, at constant risk of 'rejecting' health. On the other hand, metaphors like the 'gift of life' and the 'relay of life' focus on the organ as positive therapeutic object/person. As noted above, anthropologists have amply discussed the productive meanings of these imageries as well as their detrimental effects and ideological underpinnings. In doing so, however, they reproduce a conceptual framework that identifies both the disease and the cure with the organ, and have never moved beyond the paradigm of therapeutic intervention as a restoration of life

by means of substitution of body parts.[49] Taking the after-care into consideration, instead, means questioning whether transplantation, or any other treatment, can ever be a means to restoration of life or if it isn't better thought of as a practice of engaging with a life that has a capacity for responsiveness in itself (Davis 2012: 506).

## Conclusion

Becoming a transplant recipient is often depicted as a momentous experience that remains limited however to the phases immediately before and after the surgery. The stories told here show instead that the experience of becoming a recipient continues, in various forms, into the life after the operation and appears as an ongoing negotiation of expectations and outcomes.

For the mothers who lost their children, the life after the transplant was an unresolved process of reconciliation with the events that led to the tragic deaths of their sons. In a society where the burden of death is mostly carried by the elderly, the deaths of these children, especially to such a rare disease, are particularly 'bad deaths', which seem even more difficult to reconcile in light of the desperate effort to save their lives. In this sense, the gap between the therapeutic expectations and the clinical failure seemed to further aggravate parents' grief to the irreparable loss of a child. While the promise of the transplant prompted intense hopes and emotional investment, its tragic outcome seems to leave people without meaningful frameworks to navigate their experience of loss, thus prompting existential quandaries such as those expressed by Yuka in her constant questioning of even the most 'normal' (*atarimae*) things of everyday life.

Defining normality, on the other hand, is a question that healthy recipients too are constantly faced with. The negotiations of this normality, I have shown, takes place in a space between seeking the normality of "healthy/normal"

[49] Even Sharp's (1994: 373) analysis of disease and health in relation to body awareness remains on the level of social conventions and prejudices about body ability/disability and doesn't question the underlying medical model of therapy as a substitution of body parts.

people (*kenjōsha*) and cultivating relationships of solidarity with those who share one's own condition. One of the most important aspects of patients' experience in their life after the operation is balancing their expectations of their hardly regained health with the obligations that care requires, recipients' mutual relationships of solidarity and the networks of patients and their caregivers become an important resource to negotiate one's subjectivity as *ishokusha* against normative assumptions about health, body ability and life course (see also Tomomatsu 2013). From this perspective, patients' sociality is a way to create a community for people who belong to a minority group, or like the Japanese say, for the "nails that stick out" and that would normally "get hammered down". On the other hand, these are 'nails' that need and want to stick out. One's subjectivity as *ishokusha*, in fact, isn't inscribed only in the person's physical condition but also in his/her medical history, and in a country like Japan, which has long lacked a well-established system of organ transplantation, patients' assertion of their right to care and their deservingness as recipients of treatment are especially critical dimensions of what it means to be an *ishokusha.*

In the next chapters, therefore, I follow on from what has been argued so far concerning patient's personal experience, to interrogate how their therapeutic subjectivity is negotiated at the level of the broader moral and political economies of care. By illustrating the life after the transplant, I have shown here the more ordinary facets of the exceptional pursuit of miraculous care by means of high-end technologies. While they remain profoundly different from each other, both the existential quandaries of grieving mothers and recipients' constant renegotiation of health and normality appear as ongoing processes of engagement with a life that admits no return to normality and that is always finite and precarious. Transplant appears, in this light, as a technique by which people confront and try to tame mortality. Building on the insight that it is this certitude of the finitude of life that informs social life (Bauman 1992; Davis 2000), the next chapters investigate the fundraising campaigns for *tokō ishoku* (Chapter 4) and at the recent reform of the Act on Organ Transplants (Chapter 5) as processes to distribute the burden of death that transplantation carries with it.

*FOUR*

# "You Don't Buy an Organ, You Buy a Transplant"

## Therapeutic Citizenship and *Tokō Ishoku*

Watanabe-san was a colleague of the Satos, and one member of the fundraising committee (*sukuukai*, literally rescue group) that had helped the family collect the money for a transplant overseas. When I met her, in October 2011, she told me about a fundraising campaign that would start shortly in central Japan to help a small child receive a transplant in America. "Do people still do the fundraising to go abroad (*bokin*) now that the law changed?" I asked naively, to which Watanabe-san simply replied that despite the recent change in policy, donations were still too few in Japan.

In fact, she explained on another occasion, in the aftermath of the policy revision, the paediatric transplantation situation and travel overseas were all extremely sensitive. The reform of the Act on Organ Transplants in 2009 was meant to produce a rise in organ donations and, most crucially, to open the way for paediatric transplantation in the country, thus providing potential recipients with safer access to care than through *tokō ishoku*. But while the legal impasse on paediatric donation offered a compelling justification for *tokō ishoku*, some feared that paradoxically the new policy might, in the short term, put young children in need of a transplant in danger by affecting their chances if getting listed overseas while donations in Japan still remained very low.

At the time of my meeting with Watanabe-san, almost one and a half years since the enforcement of the reworked policy on brain death that authorised cadaveric organ procurement from paediatric patients, the official count of

organ donation, which many of my interlocutors knew by heart, remained stagnant for paediatric patients. The first teenage brain dead donor was registered in April that year, amongst polemics and accusations directed towards the JOTNW,[50] but no others had followed since, and the newly approved protocol for the legal determination of brain death in paediatric patients (under the age of six)[51] still remained unused.

People in the field agreed it was just a matter of time before the situation changed, but at what point, if any, few donations would no longer be too few was a much more complex question. In fact, Watanabe-san suggested, the more transplantation might become available, the more people would want it so that, in the end, it would never be enough and the demand for *tokō ishoku* would never end. Watanabe-san said she was aware of international criticisms of the practice of *tokō ishoku*, and of the decision of countries like Germany to tighten the conditions for accepting Japanese patients. Still, she said, for patients in urgent need of a heart, it couldn't be helped (*shōganai*): “You either do the *bokin* or you die.”

Did it really matter anyway if Japanese children were listed for transplants at home or overseas? *Tokō ishoku* after all doesn’t involve the practice of buying and selling of organs, which is prohibited under practically all international law. When Japanese patients apply for a transplant in a foreign country, they are listed alongside national candidates, and they are allocated up to a certain percentage of organs available on the basis of clinical criteria only. As Watanabe-san put it: “You don’t buy an organ, you buy a transplant.”

In this chapter, I look at what it means to buy transplants and not organs. Against the background of emerging forms of medical mobility (Connell 2011; Kangas 2007; Ormond 2011, 2012, 2014*a*, 2014*b*; Lunt, Hanefeld and Horsfall 2014; Naraindas and Bastos 2011; Solomon 2011; Witthaker et al. 2010), and in particular of travel for transplants (see also Bagheri 2013; Cohen 2005, 2002, 1999; Scheper-Hughes 2005, 2002, 2001), I explore how people negotiate

[50] The circumstances of the death came under scrutiny, with some media speculating that the boy had committed suicide by jumping under the train and he was therefore not eligible for organ donation for the Japanese policy prohibits the use of organs from people who voluntarily take their life.

[51] Fifteen years old was set as the age limit to legally give valid consent for organ donation, but clinically speaking different standards apply for the diagnosis of brain death for infant patients under the age of six.

access to care through unpacking the economies of *tokō ishoku*. I use here the idea of economies as an analytical concept put forward by Waldby and Mitchell (2006) and Yamazaki (2011a, 2011b, 2009). The authors point out that the legacy of construing organ procurement through the model of donation seems to have led to the gifts/commodities dichotomy becoming the predominant framework of analysis of both bioethical and anthropological accounts. Building on classical anthropological insights (Appadurai 1986), they therefore call for a critical appraisal of these categories, and focus on the fact that the regime of donation cannot gloss over the actual processes of sourcing, processing and distributing body parts (Healy 2006). In other words, the fact that "you don't buy an organ" doesn't mean that these therapeutic goods aren't at the centre of complex economies.

In this chapter I discuss the economies that organs are caught up in, moving from the assumption that the ways in which we circulate, appropriate, distribute and create entitlements to a 'thing' are constitutive of social orders (Rupp 2003; Hirsch and Strathern 2004). I discuss the process of fundraising and the policy on organ allocation to foreigners, and I illustrate how people give and receive organs and money, how they trade in feelings of empathy and personal stories, how they share diseases and circulate gossip, how they gauge waste, worth and burden, and how in doing so they negotiate health 'rights'.

## *Sukuukai*: the Fundraising for the Transplant Overseas

It was a windy Saturday afternoon a few days into spring. I got off my train at a railway junction just outside Tokyo, and took the walkway that connects the station to the high street shopping malls around the large crossroads in front of it. The place was packed with weekend commuters enjoying the cold but sunny day. At the busiest spot, right near the gates of the JR line, a group of children stood among the crowd handing out leaflets and collecting offers from the passers-by. Around them a bunch of people where fixing colourful banners to the ground against the wind. A quick look at the slogan on the banners and

posters all around confirmed they were the fundraising committee I had come to meet.

A few months after the interview with Watanabe-san, I knew through her that a new fundraising campaign was about to start in the Tokyo area to help six-year-old Mai-chan receive a heart transplant in the U.S.A. All set to join my first campaign, I approached the group of volunteers, handed a 1,000JPYN (~£12.50) note to one of the children holding the donation box, and introduced myself to one of the women in the group. The woman, who turned out to be the group leader (*dahyō*) welcomed my presence, was indifferent to the mention of my research on *tokō ishoku* and equally disinterested in my offer to help with the fundraising. Uncertain on what to do, I started to walk around observing what the other volunteers were doing, and spotted Takeshi among a group of other children. Next to him was Nakajima-san, apparently busy talking with a journalist. As she recognised me, she immediately came towards me with a pile of leaflets and recruited me to join the other volunteers.

With Mai's parents and the Nakajimas, was a young couple with their young son, who I later found out was another patient of Hospital J. Including these, the group of volunteers comprised some ten to fifteen people, including a few women apparently in their sixties who were habitual customers at the beauty parlour run by Mai's grandmother.

The group occupied a small but well-located area on the walkway, delimitated by the banners in pink and light blue reading: "Heart Transplant! Please help the fundraising for Mai-chan! (*Shinzō Ishoku wo suru! Mai-chan wo sukuukai! Bokin oroshiku onegai shimasu*!)." Mai's mother was standing on one side of the walkway, next to an enlarged reproduction of an article from a local newspaper that featured the same picture of Mai in her pink pyjamas, presumably at the hospital, which appeared also on the fundraising committee's website. Sato Keisuke, who joined the campaign on several occasions, suggested printing another poster, this time without the accompanying article and showing only the picture of the girl, and hanging it in a visible spot during the street fundraising to show, he said, the real person behind the campaign. Against the backdrop of the poster, Mai's mother was calling for people's attention, asking for their help for the transplant that was the only way to save

her child ("*inochi wo sukku hōhō ha, shinzō ishoku shika nai*!"). Volunteers, mostly the children, were collecting money from passers-by, while others approached people and handed out leaflets with Mai's story and the details for donations via bank transfer.

In Japan, a country with universal medical insurance, public fundraising like Mai's have become an increasingly common form of charitable donation for causes involving medical expenses. In fact, they have become the standard way in cases of paediatric transplant overseas, to the point that they are almost synonymous with *tokō ishoku*. In the past, cases of so-called self-funded (*shihi*) transplant overseas were not uncommon, paid for out of the private savings of the patient's family and through money collected within a small circle of close friends and relatives. With *tokō ishoku* becoming more frequent over the years, and with the steady rise in the price charged by American clinics, public fundraising has become a standard practice and the modalities of these charitable initiatives seem to have become standardised down to the very details of each campaign.

Hamdy (2012) describes that Egypt, like Japan, has been caught in a visceral debate on organ transplant due to the contestation of brain death. While Egypt is seen as the "pioneering" Arab country in the field of transplantation, and local doctors praise themselves on having worked on organ transplants since the years when the technology was still at its most rudimentary and experimental phase, for more than three decades the debate on brain death had rendered passing a law on organ donation impossible (*ibid.*). As organ procurement from the dead was impracticable and the medical and technological infrastructures to enable transplant were in place, Egypt developed an informal economy of kidneys, where it is not just well off patients who buy organs from the poor, but working-class families often scrape all their assets together to help the sick person pay for a kidney (*ibid.*). Strikingly similar to the situation in Japan, the Egyptian case is also profoundly different in its outcomes. As Hamdy describes in detail, several factors have brought about and continue to underpin these Egyptian transplants, including sharp internal inequalities, the international role of Egypt as an "organ selling country", and maybe most significantly the way in which the health care system

accommodates the renegotiation of ethical and unethical decisions in spite of the almost unanimous condemnation that patients, families and doctors express regarding the buying and selling of human organs (*ibid.*).

In Japan too, transplants from living donors are common. The rate of living-related donations from family members is particularly high, both for kidneys and livers, and in fact the procedure to use part of the liver in order to make transplant possible from living donors was developed in Japan as a solution to the chronic shortage of cadaveric organs. Cases of bribery to authorise illicit transplants from paid donors, which are prohibited by law, have also been reported, and, as mentioned (Chapter 1), Japanese patients are heavily implicated in organ buying and selling abroad (Shimazono 2007). Alongside this, however, *tokō ishoku* to North American and European countries has emerged in Japan as a fairly popular and highly visible response to the local shortage of organs, and while surgeons' professional connections have become the bridge for patients to travel to overseas clinics (see Chapter 2), public fundraisings campaigns are the common way for people to go about collecting the money they need for the operation.

Running these campaigns are fundraising committees named after the child called *sukuukai*, literally 'rescue group'. They are small groups of usually five to ten people, including an official representative or leader (*dahyō*), who carry out the fundraising with and for the patient's parents. No matter how urgent the need to raise money, the formation of the rescue group is essential for the campaign to begin. For families who start fundraising, then, the first step is to gather together a few close friends and colleagues who will form the group, and designate a trusted friend to act as leader. The most visible task of the rescue group is to carry out the street fundraising. These are usually organised in the area where the family lives, preferably in well-travelled places like train stations, shopping malls, stadiums and concert halls, as well as around sites such as the patient's school where people from the local community are more likely to met those who know the family personally.

Each rescue group normally sets up its own website to advertise the dates of the street fundraising and report about the on-going campaign. The sites are usually quite similar to each other in content and format. They include a blog,

kept by the family, to present the story of the patient and update details on her condition before and after the operation. They also usually include a statement about the rescue group's foundation, which defines itself as a Non Profit Organisation (NPO), committed to a transparent and accountable use of the money. A budget is also given, with a breakdown of the costs for the operation, travel, and living, alongside the overall target of the fundraising (*mokuhyō kingaku*) and regular updates on incoming donations. Through the website, the group advertises the dates of the street fundraising as well as the details of the fundraising bank account, for donations from all over the country. Another important source of money is the contributions from previous fundraising campaigns, in cases where the money remained unused because the cost turned out lower than expected or because the patient died before the operation.

## Therapeutic Citizenship

Involving the public is of essential importance for the campaigns to quickly attract generous donations, and in this sense visibility is instrumental to reach out beyond the small local community targeted through the street fundraising. The first act of a fundraising campaign is usually a press conference to publicly launch the initiative. These meetings are usually held at the local town hall or, if the patient's family is from the capital like many of my informants were, at the iconic buildings of the Tokyo metropolitan government (*Tochō*) or at the Ministry of Health Labour and Welfare. Relying on the press clubs (*kisha kurabu*) based at the city government and the MHLW,[52] or on the local branches of news corporations, these events are instrumental in order to secure media coverage, which is decisive in completing the campaign rapidly.

At the same time as they seek public attention for the sake of the campaign, these public announcements also cast the patient's case as a matter of interest for the community at large, putting the family's plea right in front of the institutions that symbolically represent public life and that, in the case of the

[52] See more on these in Chapter 5.

MHLW, are responsible for citizens' welfare. Before launching their campaign at the Ministry, the Satos had enquired about the possibility of having the expenses refunded.

> Even though we [*tokō ishoku* families] are a small minority, if we have to go abroad for medical treatment the government should have some system to support or refund the costs. There is a norm that says that if you receive medical treatment abroad in an emergency, you can have the costs refunded, even if national insurance scheme doesn't cover treatment overseas. The thing is, we were going abroad on purpose, and so they said we couldn't have a refund. It's like a blind concession they make [because] they know they can't do anything to stop you going anyway. So they don't support you, but they don't stop you […] I feel I've been treated so unfairly in this country. I mean, not by the single doctors, but by the medical system. The country is not giving these kids' a fair chance of living by not providing this medical treatment, which is clearly the most valid and effective they could have if, for example, they were born in the States. To think that, only because they're born in Japan, they have no chance is so unfair.
>
> (Sato Sayaka)

Public visibility has a strong symbolical impact but, on the other hand, often comes at the price of public exposure and can edge into intrusive scrutiny and even open criticism. Soon after their fundraising campaign was publicised, the Satos became the target of on-line polemics scrutinising their financial situation and raising suspicions around the fundraising. With jobs at one of the most important broadcasting companies in Japan, and a owning their own home in one of the most elegant neighbourhoods in the capital, Sayaka and Keisuke, it was alleged, must have had the means to afford the cost of their daughter's care. Gossip and speculation began to appear on the internet and pictures of their family home were even published on-line to hint at the fact that the family was better-off than their plea for money suggested. As the smear campaign gained speed, the Satos were accused of having organised a fraud, and the case of Aya's transplant was called a death scam.

In the midst of the smear campaign against them, the Satos stepped back in order not to further fuel the polemic, but their fundraising committee found themselves having to deal with threatening emails and intimidation. The incident put the group under much pressure and Sayaka suggested that some of their

own volunteers from less advantaged backgrounds seemed to be questioning the Satos' financial situation. NIT Japan had advised the Satos on how to run the campaign, but increasingly the issue of mutual suspicion and distrust between the organisation and some volunteers in the rescue group was becoming evident. As the fundraising came under attack tensions were exacerbated. At the same time JASOT, an association similar to NIT but notoriously on bad terms with it (see more below), stepped in, offering a donation from previous campaigns it had supervised. With this, the Satos received enough money to leave, closing a campaign that seemed characterised by a constant questioning of trust.

The accusations Sayaka and Keisuke faced were particularly harsh, and I didn't hear of other cases that had become equally violent, but people often stressed the fact that the fundraising can attract criticism and put the family under considerable pressure. Some of the families, for example, reported being questioned about how much of they would cover of the total costs of the operation out of their own savings, adding that it wasn't unusual to hear comments that suggested that the patient's parents should try and rely as much as they could on their private finances. The truth is, even in the case of relatively well-off households where both parents are in full-time employment and have good jobs, couples with small children (usually no older than forty themselves and recently married) can hardly afford to pay the equivalent of several hundred thousand Dollars or Euros. Neither can they sell or mortgage their family's house, as some were told to do, for they hope to have long years of university fees and post-operative care ahead of them. Under the circumstances, and considering that money needs to become available in a very short time, public fundraising is in practice the only viable option.

People, however, expressed concerns about this way of seeking care. While, apart from the Satos, no other family seemed to have undergone particularly problematic situations relating to the fundraising, people unanimously put emphasis on depicting how very stressful it was. Whether it was years after the campaign or during the process of carrying it out, people talked of fundraising with apprehension and nervousness and described it as incredibly *taihen*, meaning hard, troublesome and pretty awful. They usually

talked of the hustle and bustle of the preparation, of the fact that they felt unprepared and felt pressure to perform well, and obviously of the added stress deriving from the child's disease. Alongside these practical factors, however, I believe one source of stress is also the fact that the fundraising campaign brings people into the public eye, literally crying out their private plea on the street.

The straightforward assertion of one's own needs and goals is neither encouraged nor common in Japan, and what can seem like an undemanding attitude is countered by the positive expectation of the capacity to anticipate others' needs. The idea of being a burden on others (*meiwaku wo kakeru*) is a breach in mutual obligations of reciprocity. In interpersonal relationships, this means that people often go about negotiating their requests without ever framing them as such, and rely on personal connections (*kone*) to mobilise reciprocal favours. The importance of cultivating relationships of mutual support, in turn, is key to how people navigate their life as transplant recipients and how they negotiate their therapeutic subjectivity as transplant recipients both in their personal lives and in the public arena (Chapters 3 and 5). On a more political-economic level, however, relying of personal favours is not common practice.

When it comes to seeking treatment, even elective treatment, Japanese citizens can rely on a health care system that delivers high quality basic and advanced care and, at least in principle, guarantees egalitarian access to care (Campbell 1998). While sharp differences exist across various insurance plans (with employee-based schemes notoriously offering greater benefit than social health insurance), Japanese citizens have the constitutional right to universal health coverage and the percentage of the population that is uninsured is in fact significant (Ikegami et al. 2011). Under these conditions, *tokō ishoku* puts people in the precarious and exceptional position of having to ask for something that they are not entitled to.

In this sense, the general disquiet towards the fundraising that people often express is indicative, I believe, of the wider process of negotiating networks of mutual obligation and entitlement that are so embedded in Japanese notions of reciprocity. Asking for favours that are beyond one's capacity to reciprocate puts a person in the position of becoming a burden

(*meiwaku*) on others, and even receiving aid can be problematic when the 'donor' is not someone who is expected to give. Slater (2011) for example, describes how the population of Northern Japan were resistant to receiving the help of volunteers who hastened to provide humanitarian relief in the aftermath of the tsunami and nuclear disaster that hit the region in March 2011, because of the impossibility of reciprocating this favour received from strangers. As Slater notes, being indebted is not the problem, the question is with whom (*ibid.*). Indebtedness is indeed a central part of codified practices of giving and receiving that reinforce and maintain social relationships (Befu 1968; Rupp 2003; cf. Chapter 5), but becomes a burden when the debt is contracted with a stranger because one might not be able to pay it back and cannot know what could be asked in return.

*Tokō ishoku* patients and their parents variously commented on this lack of reciprocity. One of the parents whose story I told in Chapter 2, for example, said she worried the public attention their case received might lead, one day, to people asking for something back, even if just recognition, for their contribution. One of the aspects the fundraising patients' families pay particular attention to is that of publicly expressing gratitude (*kansha*) towards the contributors to the campaign, but at the same time they fear that public exposure could affect the child herself (see Chapter 3). An older patient who received a heart transplant as a child, told me for example how growing up she came to experience all the encouragement and support as a source of pressure and an obligation to do well in order to return the favour received. Their comments call attention to the so-called 'burden of the gift', which anthropologists have argued is particularly strong for organ recipients, because whether it comes from a deceased anonymous donor or from the 'sacrifice' of a loved one, the 'gift of life' remains impossible to reciprocate (Fox and Swazey 1978; Sharp 2006; Siminoff and Chillag 1999; Gordon 2001). In these cases, it seems, the 'burden of the gift' extends to both the patients and their families, because it is the parents who decide to have the transplant. Moreover, it appears to be further 'aggravated' by the fact many more donors are involved in these transplants than just the organ donor and his/her family.[53]

[53] For a discussion on how people pay off the debts incurred with *tokō ishoku* see Chapter 5.

Direct interpersonal relationships, however, are not the only channel through which reciprocity is negotiated. As Slater notes, for example, while reluctant to receive aid from strangers, the population of Northern Japan were ready to confront representatives of the Japanese government to complain about what they judged as an insufficient response from Tokyo and demand the state to do more to help them (2011). Reciprocity is negotiated here through citizenship (*ibid.*), and as Sayaka's comment above suggests, the point applies to *tokō ishoku* as well.

In fact, Sayaka's comment, which explicitly calls into question the constitutional right to health and wellbeing, was unique, as people didn't usually talk of their experience in the abstract language of health rights and citizenship. Nevertheless, the practice of seeking care abroad and raising money at home to travel overseas can indeed be seen as the negotiation of a specific form of citizenship, which has been defined as 'therapeutic' or 'medical' citizenship (Nguyen 2005, 2010; Wailoo, Livingstone and Guarnaccia 2006). Defined as a set of "claims on a global social order on the basis of a therapeutic predicament" (Nguyen 2005: 126), therapeutic citizenship identifies a need for care, denounces the fact that this is left unmet, and therefore raises the question of who should take charge of it and how. As I show in detail below, the practice of fundraising becomes the site where these moral obligations and entitlements are negotiated.

## Raising Donations

The first street fundraising campaign for Mai-chan went on for a couple of hours. At the end, we collected the banners and posters, emptied the boxes, and returned everything to members of the rescue group to return to the family's beauty salon, while a woman was passing around free drinks and envelopes containing the petty cash that was supposed to cover the volunteers' travel expenses, which most refused. The group packed their things and separated, while Mariko and I headed to a small stand serving *udon* soup with

Ai. As we treated ourselves to a hot bowl of soup after having stood in the chilling wind, Ai could finally relax.

She looked overwhelmed by the beginning of the fundraising, the generosity of so many people, and the kicking off of the campaign. It had been two years, she said, since Mai had been diagnosed and referred to Maeda-sensei, and at the start some in the family were sceptical about the fundraising and the transplant overseas. After they had come to an agreement, they registered Mai on the Japanese waiting list through the JOTNW, and at the same time they began organising the fundraising to go abroad, as they knew the chances of finding a match in the country were extremely unlikely.

Now that the process was set in motion, Ai was worried problems might rise they wouldn't know how to deal with. The family was in touch with Kanemaru-san, who had long been advising Maeda-senei's patients, but following the directives of the physician they decided not to contact associations like NIT Japan, which specialised in providing assistance with fundraising campaigns. Maeda-sensei's position on this was clear and well known. He reportedly advised all his patients to avoid involving associations other than the rescue group, a strategy, his patients often said, to further protect the families from problems like those of the Satos.

While rescue groups are in charge of these campaigns, as I have mentioned, associations do exist that offer practical assistance with fundraising. In Chapter 2, I described how NIT Japan functions as a point of reference for families considering *tokō ishoku*: Ashida-san offered his advice to families who suddenly found themselves in the position of having to seek complex and unconventional treatment, providing practical guidance on how to do so and how to run a fundraising campaign. Together with NIT, JASOT is another association dealing with the fundraising for an overseas transplant. Established in the late 1990s by Tsuchiya-san, who still runs it, JASOT is a NPO aiming, its website reads, to offer assistance to organ recipients and their families, while also promoting public awareness of organ donation and transplantation. Much like NIT, while aiming to promote organ transplantation in Japan, JASOT has come, over the years, to specialise in the more immediate task of helping recipients go overseas. It provides much appreciated support to families

seeking advice about transplant overseas, and helps out practically with organising and running the fund-raising. While Ashida-san was gradually retiring at the time of my fieldwork, JASOT was quite active.

Another campaign was the fundraising for eleven-year old Makoto-kun, which was simultaneously going on in the Tokyo area during Mai's campaign. As part of their campaign, the Makoto-kun rescue group had organised a charity concert that they hoped would attract people and help raise money. The event was scheduled on the occasion of a summer *matsuri* (festival) in a city on Tokyo's periphery. On the high street lined with stalls selling candy floss and *takoyaki,*[54] was the town hall: a bleak building quite imaginatively called the Parthenon. Inside the public, who had come for the concert, were being entertained by dancers in floral costumes and straw hats clapping their hands to the rhythm of Hawaiian music, while they waited. Next to them in the ample hall a group of up to twenty rescue group volunteers in bright green T-shirts were welcoming guests from behind a reception desk. On display were JASOT newsletters, some donor cards to pick up and the usual fundraising promotional material: the leaflets with Makoto's picture and story, the donation boxes, the banners decorated with the campaign slogans, this time thanking people for the generous support that had allowed them to reach their target in less than one month of fundraising.

The event was a display of JASOT organisational skills at their best. People were slowly allowed inside the majestic concert hall. The lights went off and the curtains opened on the wide stage. Tsuchiya-san walked in for her welcoming speech. On the back of a melodic soundtrack, she thanked everyone for supporting the fundraising and reminded us that even though the campaign for Makoto-kun was now over, it was still important to spread social awareness about the more general problem of organ donation and transplant, as the event was intended to do. Tsuchiya-san then quickly left the theatre hall to join the people from the rescue group outside, and the presenter in a long party dress took the stage and started to introduce the performers: rollerblade dancers, pop singers and a chorus from Makoto's school of which he was a

[54] Octopus pancake typically served on street stalls at festivals.

member. A few rows down from my seat I noticed Makoto-kun's family, who were visibly very touched by this last performance.

Charity concerts were a signature of JASOT's work. Along with the supervision of fundraising campaigns, the main declared goal of JASOT was to run educational activities (*keihatsu katsudō*) about organ donation. These could range from lectures in schools and meetings with medical professionals, to concerts and wrestling matches. The various things were often combined, and all were photographically documented on both JASOT's website and Tsuchiya-san's personal pages on various social networks. Former nurse Tsuchiya-san said that entertaining events were a way to reach out to the general public, a task she deemed essential to promoting a treatment like organ transplantation that depends on people's awareness and understanding. Others, however, were not entirely convinced by JASOT's approach and saw their activities as shallow, at the very best. While Tsuchiya-san's passion for public relations and glamorous events was seen, overall, as innocuous, gossip circulated around the associations' involvement in fundraising campaigns. More than once I heard speculations about JASOT using the money from the campaigns to sponsor activities such as the annual day-off of patients and rescue groups volunteers; and on a couple of occasions, people even brought direct charges against the association.

> I can't say it with absolute certainty, but I've got the feeling they are actually working just for the money. Don't write this down –I'm speaking without proof– but my impression is that they don't have pure (*junsui*) intentions. For example, they don't pass on the money that remains from closed fundraising to other people in need. I know a family who asked them for help and didn't get any money, and eventually the patient died. They could have given it to them; it's not their money after all. They're only intermediaries to raise the money for others. In some cases, when a patient dies, the family cannot even use the money from the fundraising for the funeral expenses […] I think in the end [money] is what they're really after. And what do they use it for? If a family is in immediate need, they should give it to them. They act as if the money is their own, but it's not.
>
> (Anonymous)

The people I interviewed seem to have different opinions about JASOT; most were generally indifferent, some were notoriously on bad terms with the

group, but never explicitly voiced their criticism to me; no one, it has to be noted, testified to instances in which JASOT had appropriated money. The charges against the association, in fact, didn't even classify as proper accusations of fraud, but rather pointed to what was perceived as an improper use of the money deriving from the fundraising, stressing the fact that JASOT allegedly decided how to redistribute the funds remaining from the campaigns it supervised.

Humanitarian work, Bornstein (2012) argues, is evaluated through moral discourses, and any suspicion or distrust creates a space for auditing the work of the actors involved. The rumours surrounding the credibility and accountability of JASOT, like the false accusation of a death scam against the Satos, articulate discourses that gauge, contest and validate the worth of fundraising for a transplant overseas. As a sort of 'meta-commentary' (Bornstein 2013; cf. Bonhomme 2012) on the transactions at stake, suspicions and allegations called into question the use and misuse of money. Money was associated with self-interest, and depicted as potentially corruptive and even disruptive of social ties (cf. Taussig 1977), asserting by contrast the moral value of the 'pure donation' to worthy recipients as a form of 'pure gift' (cf. Parry 1986).

That the money/gift distinction is socially constructed is anthropological common sense (Parry and Bloch 1989), and in fact donations of money are usual in Japan (Rupp 2003). Rupp however shows that when money is donated, notes are wrapped in particular envelopes to be presented, and even though people reciprocate presents on the basis of a financial calculus, the price of these elegant gifts purchased in big shopping malls is expressed with a special code so as to not to reveal the price of the item in too blatant a way (*ibid.*). The role of the rescue group is precisely to appropriately construe the donation of money, and indeed besides the practical help given to the campaign, the very reason of the *sukuukai* is, as I see it, to create accountability for how the money is collected and used and thus to validate trust and the social worth of the fundraising.

The reason why this is so important is because public fundraising escapes codified circuits of reciprocity. They are a form of secular, contemporary charity

that rests on free and voluntary donations from strangers. Friends, families and colleagues of the rescue group are only the first link in a process that reaches out to a wider public; campaigns like the one for Mai-chan are carried out in urban contexts where the very idea of a local community is fragmented and fluid, and media reports and bank transfers are often the only mediums that link donors and recipients. Trust then ties into the broader politics though which people ask for what they cannot reciprocate.

## Wasted Lives and Shared Diseases

Fundraising for the transplant overseas is a way to call attention to the needs of what Duffield call ‘uninsured lives’, that is lives that have no enforceable entitlements (2008; quoted in Benthal 2012). As seen above, resting one’s quest for care on the voluntaristic support of strangers for their uninsured needs puts the families of young organ recipients in a vulnerable position. The duration of the campaign and the very possibility of leaving depend on the generosity of donors, while at the same time having to appeal to forms of support outside of those institutionally recognised, means that families can only be passive (and grateful) recipients of aid. For all these reasons, the fundraising is also a way to endorse deservedness. In a way similar to that Slater describes with regards to how the tsunami victims articulated their claims, the fundraising becomes a way to renegotiate some sort of reciprocity by pointing out that the people asking for help have given already, for they have suffered enough (cf. Slater 2011).

The people interviewed described the fundraising as the most emotional passage in the 'hurdle race' towards the transplant (see Chapter 2). Interwoven with the distress and worries about it, were equally overwhelming feelings of empowerment and hope.

> [The time Shuichi was ill] was the saddest, toughest, most miserable time. But on the other hand, it was also the time we fought the hardest for his life, the time we got together as a family and we did everything that was possible for him to live. It was the time we

> endured (*gambatteita*) the most. In another way, though, because we pushed ourselves the hardest (*ichiban isshōkenmei*) we were also left completely wrecked because of the actual situation as well as because of the complete loss of hope. Of course I'd wish Shuichi could have overcome the disease, but if I look back now I think even being ill would be fine if we could go back. I'd go back even to that time. In the end we were happy just because we could try (*gambaru*) together. But you just don't realise it when you are in the process.
>
> (Kumano Natsuko)

As Natsuko's comment highlights, the fundraising brings to life the dynamics tangled up in the idea of *gambaru* (see Chapter 2). It manifests hope in the form of a proactive effort that aims at a very concrete and measurable result (raising enough money to leave). At the same time, it brings the family closer together in the shared experience of enduring a problematic situation, and similarly to what Franklin notes about IVF, it becomes an almost self-fulfilling experience (1997).

> It was hard. I had to set up the group and asked friends to help. Of course, no one had any experience of this kind, and we knew we'd have to deal with a lot of money. And then people have their own lives, and the activities of the group were kind of adding on top of that, so it was really hard. On the other hand, you know, there were times when one year might pass without me being able to make an appointment, or meet my friends, and still when I asked for their help everyone was so supportive. I felt extremely grateful (*kansha*). In such a situation it is easy to think you're alone, but I realised I was not alone at all. People were so involved and supportive. It made me feel really lucky and grateful (*arigatakatta*).
>
> (Ono Yuka)

Emerging from Yuka's comment is the fact that in many respects the fundraising can be a moment of change in the experience of illness, which up to that point has been both disorienting and alienating (cf. Chapter 2). When the patient is hospitalised in a critical condition, the lives of the parents, especially the mothers, can be completely absorbed into caring for their child, confining them to her bedside, and largely away from social relations outside of the hospital. In contrast to this, the fundraising brings the patient to the centre of a collective effort to save her life. I this sense, it doesn't only provide a practical

aim and outlet for action, it also mobilises collective emotional and symbolic support.

Through the rescue group, the fundraising brings to life the humanitarian ethos of *tokō ishoku* as a sentiment of empathy that translates into a gesture towards a fellow human who is suffering (Fassin 2007). Fassin argues that through this emphatic identification with the subject of aid, humanitarianism works as a politics of life, in that it gives specific value and meaning to certain forms of life; it identifies lives that need to be rescued, sometimes at the risk of putting others at risk (*idem*).

Nowhere could these lives be more powerfully represented than in the image of sick and innocent children, who would potentially have access to life-saving treatment if only they were not in Japan. During my fieldwork I was often left wondering about the wide use people made of the images of young *tokō ishoku* patients. These pictures were frequently shown in media reports about, as well as in promotional materials for, the campaign, usually representing the babies and children on their hospital bed, often with an oxygen tube in their nose. While expressing concerns about possible repercussions of this exposure after the transplant, parents (as well as adult patients) seemed comfortable in disclosing sensitive, and at times visually impressive, aspects of the illness.

The stories these pictures tell, I believe, represent the children as victims (cf. Fassin 2013) in the name of raising money, and are interwoven with an assertion of the deservedness of their plea. As they show the most tragic aspect of the child's disease, these pictures offer the opportunity to intervene. They announce that such deaths shouldn't be, not in this way, and not in these conditions. Drawing on Fassin's insight that humanitarianism identifies a 'waste of life', Davis argues that this waste is what differentiates normal from pathological mortality (2012). A 'waste of life' is a 'surplus of mortality' compared to what society can tolerate, and it therefore comes with the moral obligation to intervene and do something to remedy it: a 'waste of life', Davis notes, no longer raises the question of what can be done, but powerfully elicits the immediate response that something *has* to be done (2012: 509). Along with the giving and receiving of money, fundraising thus creates a trade in empathy

that upholds and validates the families' pursuit of care, and mobilises spontaneous support in the form of a moral obligation to help those in need.

## Systematic Exceptions

In the noisy café near Tokyo station, where we met after her work, Takada-san barely had a sip of her tea as she went animatedly through the story of her son's transplant. She was very talkative and seemed to be enjoying the conversation and to be in no hurry to return home, although her family was probably waiting for her to come and have dinner. After she told me her story in captivating detail for about two hours, the conversation began to go astray. Maybe she did want to go home for dinner, I thought, as I switched off my IC recorder and collected my notebook. At that point, Takada-san quickly resumed her narrative, to tell me of when her son received the transplant. In fact, she said in a tone both hesitant and severe, he received two.

Soon after the surgery, their child suffered a major rejection crisis. He was admitted to intensive care and was eventually listed for a second operation. A suitable donor became available relatively quickly; the transplant this time was a success and the boy was discharged and returned home in a few months. The family, however, had run out of money to pay for the extra treatment and for the second surgery, whose costs were not calculated in the initial budget. While they waited for the second operation, the Takadas had to re-open a second fundraising (*saibokin*), but this time the campaign lacked the momentum of the original initiative and they feared that raising the money would be much harder. The hospital didn't refuse care to the family, but it took the Takadas two years (compared to the couple of months of the first campaign) to settle their debt, which had risen to almost two hundred million JPYN, more than twice the target of the first campaign.

> It was a huge hospital, a public facility, and that's one reason, I think, why they were not so strict about the payment. But even though it was a public facility, as foreigners we had to pay for everything. And we were not Mexican immigrants: the Japanese have money, so we

> had to pay up to the very last penny. Our doctor had been very clear about this point. Otherwise, he said, the [American] hospital could turn down the next [Japanese] child.
>
> (Takada-san)

Second transplants are not rare and recipients might need one at some point down the line. It can be following years of good health, or immediately after the operation. In the case of Suzuki-san, which happened a few years ago, a second operation became necessary while they were still in America. Shortly after the transplant, Suzuki-san's daughter was discharged and moved in with her parents in a flat near the hospital. The family had planned with the physicians to save money on the hospitalisation fees in order to make sure they could afford to stay in America for a few months after the operation and let the girl receive the follow-up care she needed at the local hospital.

After an initial positive recovery, however, her condition worsened and she got to the point where she would need a second transplant. The problem was, according to American policy, non-resident patients can be allocated only up to a certain share of available organs. The quota is officially set up by the United Network for Organ Sharing (UNOS) as 5%, and is calculated on a hospital by hospital basis. The transplant programme the Suzukis had been accepted onto was at a relatively small centre, with an overall number of operations of about twenty per year. Suzuki-san's first transplant, it turned out, had already taken up the quota destined for foreign patients.

Sticking to the quota would mean failing the patient and her family. As already discussed (see Chapter 2), the dynamics of the patient-doctor relationship weigh heavily on clinical decisions concerning these procedures so that, whether it is about arranging to send patients overseas from Japan or listing a non-resident candidate over-quota, the decision would not be a strictly bureaucratic one. As one of my interlocutors put it "it's people who run medicine" (*iryō ha ningen ga ugokasu*).

One possibility would have been to list the family at another centre, but the medical team reckoned it would be clinically better to avoid the transfer, which would also spare the family a further financial burden. The Suzukis were thus told that by "stretching the UNOS rules a little bit" (*ruuru wo ugokasu*) a space

was cleared for them. Suzuki-san was hesitant, fearing it might compromise their doctor's position, but after consulting with another member of the medical team, he accepted. Years later, he still talked of the experience with a mixture of gratefulness and apology (*hijō ni kansha shite, mōshi wake nai*).

In telling these stories, I too am bending the rules of privacy and confidentiality a little bit, for both Takada-san and Suzuki-san asked me to omit these details. The reason why I am including them (omitting any details that might make their stories identifiable) is because these second transplants do not constitute, in fact, a break of UNOS policy. Below I discuss in more detail the American policy on the allocation or organs to alien patients; what I want to note here is that the request not to report certain details is indicative, like the rumours of which I told above, of the fact that the matter is perceived as a sensitive one.

In both these instances, the decision to list the patient for a second transplant was indisputable. Clinical ethics are always about people, not policy; and the decision not to treat these patients because of their nationality would have been unethical. The reason why these cases were discussed as problematic is another one. The campaigns for transplants overseas are shaped by a humanitarian ethos that casts every child's story as an emergency. But emergencies are states of exceptions, where rules can be bent because immediate solutions need to be found. But what about when exceptions get reiterated? These second transplants raise the question of what rules apply when exceptions become systematic, as in the phenomenon of *tokō ishoku* taken at large. From this perspective, if the humanitarian spirit of *tokō ishoku* rests on the principle that every life *should* be saved, policies on the allocation of organs are informed by the assumption that organs are scarce resources and not every one who needs one *can* receive it.

## Calculated Gifts, Self-Sufficient Reciprocity

In a regime of scarcity we are constantly made aware that organs are not only altruistic gifts, but also scarce resources. Every day, we are told, patients die

while on a waiting list for a transplant, and excessively long waiting times have replaced underlying conditions as a cause of death. Fairness in the allocation of these limitedly available and potentially life-saving therapeutic goods has been one of the critical ethical issues at the core of transplantation since its inception (Fox and Swazey 1978; Koch 2001), and continues to remain so although the scope of the problem has somehow mutated. Currently, no national programme or international cooperation scheme is able to meet the demand for organs by prospective recipients; scarcity, we are told, is a global phenomenon, at least in countries that run resource-intensive medicine like transplantation. At the same time, the phenomenon of travelling to foreign countries for organs which only a few years ago was treated as a urban myth (Scheper-Hughes 2001) has increasingly become a matter of concern, as raises the issue of fairness in the allocation of organs on a global scale.

In 2008, the Istanbul Declaration on Organ Trafficking and Transplantation Tourism was issued to tackle the phenomenon of patients' mobility across borders in pursuit of organs (see Chapter 1). The declaration identifies and defines different modes of international mobility related to transplantation[55]. The position adopted by the document is that the movement of organs, donors, recipients, and health care professionals is to be considered an ethically condemnable practice when it amounts to organ trafficking (which involves violence and coercion) and/or transplant commercialism (the practice of trafficking, buying, selling or using organs for financial gain), and when the allocation of organs and health care resources to foreign patients undermines the local population's access to transplantation. The declaration also recommends the development of national policies aimed at providing a sufficient number of organs within the country or through cooperation schemes. Further endorsement of the principle came in 2009, when the WHO updated its guidelines on transplantation urging member states to strive and achieve self-sufficiency in organ procurement at the national level (Noël and Martin 2009).[56] Japanese transplant recipients built on the growing international attention to the

[55] http://www.hks.harvard.edu/cchrp/isht/study_group/2010/pdf/DeclarationOfInstanbul.pdf
[56] http://www.transplant-observatory.org/SiteCollectionDocuments/wholegethgp.pdf

problem to successfully lobby for a reform of the law on cadaveric donation (see Chapter 5), but even as the effect of the changes in policy were slow to take place for adults, paediatric patients still continued to rely largely on travel to America.

America is not the only country providing transplant services to privately paying non-resident aliens, including Japanese patients. In the 1980s, the UK was the destination of the first *tokō ishoku* recipients in need of a heart transplant they couldn't get under Japanese law[57]. Australia was also a common destination. France and Canada too are reported to have occasionally provided transplants for Japanese patients, and until recently Germany was second only to America in the number of patients accepted[58]. Many of these countries, gradually closed their doors to Japanese patients as professional connections between the countries were broken (as in the case of Kitakana-sensei who returned to Japan) or because, as some interlocutors suggested, the practice became politically sensitive.

That has so far not been the case in America, which from the 1990s has become by far the main receiving country of Japanese *tokō ishoku* patients. As seen through Suzuki-san's story, UNOS has a specific policy on the inclusion of non-US citizens on waiting lists, that sets a 5% cap on organs allocable to foreign candidates. Recipients' selection is subject to the same criteria that apply to national patients while acceptance of potential candidates from abroad is at the discretion of the transplant programme and is conditional on the payment of a first settlement of the overall fees. The so-called 5% rule was introduced in the mid-1980s to control access to transplants by privately paying foreigners. It is officially justified on the grounds that every year a certain number of non-US citizens become organ donors in America, and aims to provide indiscriminate care regardless of nationality while also avoiding the waste of transplantable organs (Blumstein and Sloan 1989). Since its approval, the policy has been debated and revised, and the cap brought down from an initial 10% to the current 5%. More recently, UNOS has decided to implement stricter controls to facilitate the audit of single transplant centres and collect

[57] See 'Stories from Harefield', published by the patients' group New Heart Club, for stories of the first Japanese heart recipients travelling to the UK.
[58] See MHLW (2006) for a report on the practice of the transplants overseas from Japan.

data on recipients' nationality in order to evaluate the phenomenon of patients travelling to the U.S.A. for transplants and increase public transparency.[59] Like the fundraising, it seems, the allocation of organs to non-resident patients calls forth scrutiny and demands accountability[60].

## A Case for Comparison

Wailoo and Livingston (2006) tackle the issue of medical citizenship and the allocation of organs to foreigners though the story of Jesica Santillan. Jesica was a seventeen-year-old girl who illegally entered the U.S.A. from Mexico in the hope of receiving medical care for her heart condition. Jesica's family settled in North Carolina; the girl enrolled at a local school and her mother found a job as a cleaner, becoming eligible for medical insurance. As her condition worsened, Jesica was diagnosed as being in need of a heart transplant. Through the support of her school and local institutions, her plight came to the attention of a wealthy entrepreneur who helped the family pay the fees for the girl to be accepted at Duke University Hospital. Through a medical mistake, however, Jesica received a set of heart and lungs of a different blood type, resulting in a violent rejection that almost killed her. While the girl was in a deep coma and on life-support, the decision was taken to list her for a second operation, even though her chances were slim. Ten days after the first surgery, a new donor was found for the second transplant, but Jesica didn't survive the operation. After her death, a harsh debate raged over her case. The clinical utility of the second transplant was contested, as was the decision of using yet more precious organs for a patient who was unlikely to survive and who was illegally in the country in the first place.

Commenting on the case, Livingston argues that in a regime of shortage where organs are perceived as scarce and endowed with almost miraculous

[59] As from UNOS policy at:
http://optn.transplant.hrsa.gov/PublicComment/pubcommentPropSub_290.pdf

[60] The question of whether organs should be allocated to foreigners easily fuels suspicions of private patients jumping the queue (Guardian 2009; BBC 2009; New York Times 2011), and is further exacerbated by highly visible cases, like the one of the Japanese gangster receiving a liver transplant in California (Los Angeles Times 2008).

therapeutic power, waste becomes a morally loaded concept. Resonating with this argument, Natsuko commented on the fact that since Shuichi had died before the operation this, at least, spared the waste (*mottainai*) of precious organs, which she feared would have further aggravated her grief. Similar to the concept of burden (*meiwaku*) discussed above, waste marks the boundary between entitlement and the lack thereof, revealing how the negotiation of moral obligations involves inclusion and exclusion within circuits of sharing, giving and receiving.

Commenting on the politics of inclusion and exclusion in these networks, the authors observe that just as Jesica's age and gender had played a role in casting her as a subject worthy of philanthropic aid, so her nationality and legal status as an undocumented immigrant roused the public's outrage at the waste of organs after her death (Wailoo et al. 2006). Recasting the controversy over Jesica's second transplant, the authors show that while the organ donation rate among Latino immigrants is higher than the national average, as non-US citizens, they encounter more difficulties in accessing health care, and are more likely to be turned down by hospitals that provide transplant services to foreigners because of their irregular visa status. Immigrants, it appears, donate more than they receive, reflecting the contribution they make to the society in which they live, and their inclusion as appropriate recipients of philanthropic policies (be it in the form of organ allocation or financial aid as Jesica received) can be considered a form of "justice as reciprocity" (*ibid*.: 207). Through Jesica's case, the authors convincingly demonstrate how (medical) citizenship is not a simple category, but a morally and politically charged one, inviting us to think for example about how public perception would have been different had the girl been in America on a student visa.

One might as well ask whether, and how, anything would change if the patient in question entered the country as a temporary visitor on a medical visa. The first difference in this regard is that, contrary to the public outcry over Jesica's two transplants, no similar critique exists, to my knowledge, about the practice of *tokō ishoku*, so that despite the visibility of the campaigns in Japan, the phenomenon seems to pass largely unnoticed by the general public outside the country. The steady flow of Japanese recipients to American hospitals

doesn't seem to be perceived as a disturbing factor in a political economy of organ allocation that is framed as 'zero-sum game' (Wailoo et al 2006: 120).

Jesica's case is an interesting contrast to the ethnography of Japanese *tōko ishoku* patients, and the two illuminate as well as complicate each other. Representing and defining these networks of moral obligations is, as the comparison suggests, a contested process negotiated through categories that are as mutable as patients are movable. The way foreign recipients are perceived as either a threat or deserving subjects in need, is not inscribed in their personal history alone, let alone in their biology, and patients' therapeutic citizenship is deeply informed by the modes of patients' mobility across national and jurisdictional boundaries (cf. Ormond 2011, 2012). This also means, however, that there exist structural factors that put individuals in the position of becoming caught in or released from networks of reciprocity, of benefitting or contributing to them, of being more likely to give or to receive. In her analysis of Jesica's story, King (2006) argues for the need to promote a discussion that can move from the scale of the individual "identified life" to that of system-level conditions, such as access to and costs of care, which are often ignored.

## Burden and Belonging

The fact that *tokō ishoku* doesn't raise American outrage as Jesica's case did doesn't mean it is regarded as unproblematic, at least on the Japanese side. In a political economy of scarcity that is framed as a zero-sum game, "a Japanese going abroad for a transplant is a lost chance for another person in that country to be helped" (Komeno-san, *personal communication*). As many organ recipients do, Komeno-san wrote an anonymous letter addressed through UNOS to the donor family to express their gratitude. In the testimony he gave during a parliamentary hearing on the reform of the policy on paediatric donation, Komeno-san declared that his family didn't feel like disclosing their nationality to the American donor's kin.

> We wrote a letter to express our gratitude. However, in that letter, we actually didn't feel like revealing that we are Japanese. We felt truly regretful (m*ōshiwakenai*), and we couldn't write such information. They probably decided to donate wishing that a part of their beloved child would live on, but I think they really couldn't imagine (*totemo sozō dekinai*) that those organs would end up going to a country as far off as Japan.[61]

The gift metaphor plays a crucial role in upholding the enterprise of organ procurement and metaphorically endows the act of donation with symbolic power, not least that of fostering social solidarity (Titmuss 1970; Hogle 1999; Healy 2006; Waldby and Mitchell 2006). Komeno-san's experience reveals, on the other hand, how *tokō ishoku* challenges these representations as it cuts across imagined networks of belonging.

> Going abroad is a last resort when nothing more can be done (*shōganai*). In the case of cardiac transplant, for example, you cannot know that, on average, when you're told you need a transplant it means you've more or less one year [left]. It depends from case to case obviously but that's that's how much time you've got to live. Waiting in Japan, where chances are so few, then you're going to die (*shinjaikenai*). So people [who go abroad] have really no other possibility (*shōganai*). If I were in their position [again] –well, you never really know until you are, but– if I happened to be in the position [now] I'm pretty sure I'd go. To stay means to die, and if you don't have a chance of surviving, then it's not even a matter of choice: if you're going to die, there is nothing that can be done (*shōganai*). […] It's inevitable. The transplants overseas are inevitable. If you look at the individual Japanese [patients] one by one (*kojinn kojinn sureba, nihonjin hitori hitori*), the transplants overseas cannot cease; they are just inevitable (*yamu wo enai*). But as a country (*kuni toshite ha*), that is condemnable (*yurusarenai*). That a developed country like Japan continues with such a practice needs to be condemned. [When I testified at the Diet] I said that: the problem is not about transplantation medicine; it's about whether or not Japan can make it without being a burden on other countries (*meiwaku wo kakenaide*). When it comes to organ transplantation, there are always so many issues involved, starting with brain death, but the problem was about whether or not Japan, as a country, could make it without continuing to be a burden on others. What kind of trade (*shōbai*) is that if not a burden? You receive life from others and what do you give back? That's the worst thing.
>
> (Komeno-san)

[61] From Komeno-san's testimony as at: http: http://www.shugiin.go.jp/internet/itdb_kaigiroku.nsf/html/kaigiroku/018716920080603001.htm

In Komeno-san's analysis, burden, like waste, becomes a morally loaded concept that defines boundaries of belonging and mutual obligation, or lack thereof. Drawing such boundaries along the lines of national identity and citizenship, Komeno-san clearly identifies the state as the primary bearer of citizens' health rights, reflecting the way in which the issue of *tokō ishoku* was mobilised to lobby for a reform of the Japanese law on transplants (see Chapter 5). On the other hand, however, his reconstruction lays equally strong emphasis on the fact that *tokō ishoku* is driven and justified by the assumption that health and life itself are essential human rights. *Tokō ishoku*, it seems, exists at the intersection between different rationales and apparatuses of health-care provision.

As anthropologist Redfield describes, humanitarianism, which I have shown underpins the fundraising campaigns and the acceptance of foreigners on the waiting lists, attends to the expectation that every life should be saved by deploying strategies of intervention that stretch beyond the bureaucracies of the state as the main health-care provider (and sometimes of the promises of corporations and civil society as well), and enter another sort of market (2012). In this way, while the language of health rights should protect against the danger of a neo-liberal approach to health care (represented for example by user fees and unequal conditions of access), the opposite can be true as well. Reubi (2011) argues that when non-state actors, like private corporations, civil society groups, or in this case, charitable foundations and private hospitals, become the main health care providers, the promise of health rights can in fact become a deception, exacerbating rather than countering trends of market fundamentalism.

> To tell you the truth, when I was in America I asked my doctor whether they'd stop accepting Japanese patients because of Istanbul Declaration, but he told me that was not the case. It might sound bad put this way, but America is a capitalist society. "As long as you've got the money (*okane sae areba*)," he said, "you can have the operation."
>
> (Morinaga-san)

Morinaga-san was the mother of a baby girl who died after a transplant in America. Like many patients' families, she was still in touch with the doctor who

had treated her daughter, and was overwhelmingly positive about her experience abroad. Her comment was not indicative of a critical stance on the system of paid transplants as a form of transplant commercialism (see more below), but was nevertheless revealing of the problematic nature of money in these transactions. In a system where the only condition of access to care (*sae*) is money, that which create no relations[62], then no obligation exists. While Morinaga-san's comment suggests that under a profit-oriented management of health resources money will always guarantee access to care, the dependence on money also reveals that the conditions under which such access is granted are inherently unstable.

In this respect, one of the rumours that circulated around the involvement of money in the journeys overseas for transplants concerned the price of the operation. Patients' families and professionals in the field sometimes alluded to the fact that Japanese patients were allegedly charged higher fees than those the American hospitals would normally charge local patients, and that the price was rising rapidly. In 2009, at the peak of the debate on the law reform following the publication of the Istanbul Declaration (2009) and the WHO guidelines (see Noël and Martin 2009), the *Yomiuri Shinbun*, one of the major national newspapers, published a report on *tokō ishoku* alarmingly titled: 'The truth (*honne*) behind the price rise: excluding the Japanese' (2009b). In the article, it is suggested that the target of fundraising campaigns had risen from an average of 65.000.000JPYN (£344,500) in 2002 to 170.000.000JPYN (£901,000) in 2008. The investigation revealed that, whereas in the mid-2000s the maximum cost of a heart transplant in the U.S.A. (if no post-operative intensive care was required) was 70.000.000JPYN (£371,000), all the four families who travelled to America in 2008 reportedly paid more than 80.000.000JPYN (£424,000). Cases were known of patients who were asked for up to 200.000.000JPY (£1,060,000), and in one instance a family was presented with the request of a 400.000.000JPN (£2,120,000) deposit in order to list their daughter for a heart transplant. The picture of the father of the young girl in front of the *butsudan*[63] with the picture of his late daughter opened the

[62] See Simmel (1907), Marx (1867), cf. Maurer (2006).
[63] Home altar to the family's dead.

two-pages report. In the interview he released, the man denounced the conditions set up by American hospitals, saying that while he was aware that transplants overseas are normally very expensive the request of a 400.000.000JPYN (£2,120,000) deposit was simply "unreasonable" (*hōgai sugiru*) (*Yomiuri* 2009b).

Quoting a Japanese surgeon based in American, the *Yomiuri* article suggests that the rise in price was used as a financial disincentive to limit the number of Japanese patients, who in some facilities had allegedly taken up the quota of organs available to foreign patients (*Yomiuri* 2009b). The idea that money can work both as a means of access as well as a disincentive brings to light its flexibility in negotiating patients' inclusion and exclusion, revealing how such flexibility can easily become synonymous with instability. Arguably, the worries and distress the families of young patients express towards fundraising highlight the fact that relying on money to obtain care was not perceived as a shortcut to receiving safer and faster treatment but rather was experienced as a profoundly vulnerable condition to be in.

The most striking figure in the *Yomiuri* article, however, refers to another issue often mentioned in relation to the economic aspect of *tokō ishoku*. While the costs of a transplant in America was, on average, of 80.000.000JPYN (£424,000), the same operation in Germany cost 'just' 40.000.000JPYN (£212,000). But like people commonly noted that the waiting times in the two countries were quite different.

> [Going to Germany] is different. I send some patients to Germany because everything is legal, and I mean legal-legal. That is, it's not just legal in Japan; it's also legal in Germany, it's common sense. They [Germany] have the 5% rule for foreign patients. Then, of course, you need money, but it's exactly the same money German patients would spend. That's the big difference. And the waiting times too are the same, so you have to wait one or two years. The conditions are the same: the money is the same; the waiting time is the same. That's ok; if you keep within the 5%, it's ok.
>
> (Kitanaka-sensei)

Kitanaka-sensei's emphatic description of the relation between costs and waiting times in America and Germany underlines the idea that the concept of

fairness (legality, in his terms) is not just a matter of policy. While Japanese patients reportedly receive transplants as quickly as a few weeks after their arrival in the U.S.A., their experiences appear to contradict the litany of fatally long waiting times that we are all too familiar with. As one can easily guess, the rapidity of the operation, coupled with the fact that Japanese allegedly pay more fees in advance of the operation, easily gives rise to the suspicion of queue jumping.

Most of these rumours about transplant commercialism, however, are unverifiable or untrue. Like the surgeon quoted by the *Yomiuri Shinbun*, some speculate about the consistent volume of Japanese patients treated in America. Given a lack of information about the nationality of foreign recipients and without records from the single transplant centres, these rumours remain difficult to assess, and the fact that some medical facilities might present a high concentration of candidates of Japanese nationalities is not completely unlikely. On the other hand, however, UNOS data show that in none of the organ procurement regions into which the country is divided is the quota of the 5% met, let alone taken up by patients of any particular nationality. In fact, at least at a national level, fewer organs than those potentially available to non-US citizens are in fact allocated to foreigners. The life histories collected do indicate that patients treated in the U.S.A. do indeed have shorter waiting times compared to other places, and that waiting times seem to be sharply different in America and Germany. This, however, is no proof of bribery in order to push patients up the waiting lists. First of all, the reported gap in waiting times doesn't take into account difference between the German and American systems, which are hardly comparable. Further, it reveals nothing about the condition of the patient at the moment of being listed, or whether this can affect the choice of the family to travel either to the States or to Germany. In fact, as seen in Chapter 2, patients are already in a particularly severe condition when they leave Japan, and so to think that they are classified as highly urgent priorities is not at all unreasonable.

On the other hand, it is indisputable that the system of *tokō ishoku* allows patients to by-pass and rely on some structural characteristics of both the sending and hosting health care systems, and to work around them to their

advantage. As I argued, the fundraising for the transplant overseas rest on a specific moral economy that focuses on vulnerable and identifiable lives. Furthermore, they exist within a local political economy in which the demand for resource-intensive and elective treatment can be framed as absolute because the scarcity of organs glosses over any other boundary that potentially constrains one's pursuit of health care. On the other hand, Japanese patients can rely on international professional connections that allow them strategic access to treatment in another system, like the American one, which is ridden with inequalities. Most notably, once back home after surgery, Japanese patients can rely on insurance coverage for the expensive post-operative care that many American recipients struggle with, and that can constitute a major impediment for local patients to get listed in the first place (Hoffman 2013)[64]. But the flexibility of the system is also its vulnerability, both at the level of the lived experience of individual patients' families and, as the next chapter shows, on a global scale.

## Conclusion

The movement of people, money, health resources, and body parts on a global scale seems to have become an increasingly common reality as well as a question of growing academic and public interest. Against this background, *tokō ishoku* presents itself as a particularly interesting case of medical mobility. The phenomenon of transplants overseas from Japan intersects with long-standing questions concerning the role of the market and the regime of free donation in relation to the procurement and allocation of organs, while at the same time, it opens the debate on justice in the distribution of scarce recourses, traditionally at the core of transplantation ethics, to new dimensions of public health as an increasingly global problem.

In unravelling how these issues came about and are tackled through the phenomenon of *tokō ishoku*, in this chapter I discussed the political economy of

[64] See also Sharp (1999, 2006) on the problem of lack of medical insurance and after-care compliance among American transplant recipients.

transplants overseas by describing the process of fundraising and the American policy on allocation of organs to foreign recipients. Throughout my analysis, I have shown how the transactions involved in the transplants overseas blur and reinforce, draw upon and challenge familiar boundaries. If the anthropological argument that gifts and commodities, such as rights, citizenship and justice, are not fixed categories inscribed into things themselves is accepted, the case of *tokō ishoku* shows how such distinctions are blurred and reorganised in practice. As it does so, *tokō ishoku* invites us to adopt an analytical gaze that is indeed as movable as patients are, one that can adjust to the different scales of the problem (from the individual plea for help to global systematic conditions of access to care) but also, more critically, try to reconcile them.

In this sense, *tokō ishoku* appears more complicated than the immediate need to rescue a life in danger or to be presented as percentages in a policy. Equally important, the questions attending the phenomenon –how sustainable it is, and what place it occupies in the panorama of both Japanese and global health care– are open to change as is the situation of transplantation. In looking at how people conceive things in practice, the analysis I propose offers a complex and dynamic framework through which to understand these issues. One last thing, however, has so far remained out of sight. The networks through which people give, receive, share, (contain) waste, claim entitlements and create belonging, are ultimately ways of distributing what they don't dare to include: death. Just as policies about organ allocation are ways to fairly account for death against the life-saving power of organ transplant, so the fundraising is a socially orchestrated practice to evade death: to make tolerable when it cannot be avoid by mobilising all the available collective efforts.

While *tokō ishoku* remains, in practice, the safer way to access care for Japanese patients, its inherent vulnerability becomes the lever to promote reform of the national policy on cadaveric donation and reignite, after decades, the controversy over brain death. Building on the ideas of reciprocity and mutual obligations introduced here, the next chapter thus looks at the transplant advocates' lobby for reforming the law on brain death and transplants.

*FIVE*

# Giving Back

## Patients' Advocacy and the Reform of the Act on Organ Transplants

Doing fieldwork on organ transplantation rarely offers the chance of attending glamorous events. The night of October 27th 2011 was an exception. On the occasion of the Tokyo International Film Festival, the Asian premiere of the *Power of Two* was screening at the fashionable Roppongi Hills complex. This American documentary is a biopic of twin sisters Isabel and Anabel Stanzel, transplant recipients turned advocates. The screening in Tokyo was a particularly important one in the promotional tour. Reflecting the sisters' Japanese-American heritage, the storyline is divided between the two sides of the Pacific and shows how, in Japan, the "cultural problem" with brain death has long affected the possibilities of patients to receive care. The movie tells the stories of some Japanese patients, including the of bereaved family of a *tokō ishoku* child, leading on to the inspirational footage from the vote on the reform of the Act on Organ Transplants in 2009, where patients' families are shown wiping their tears as they witness the final deliberation at the Diet.

At the party that followed the screening, Nakamichi-san, who had organised the event with the JOTNW, chaperoned Ana and Isa, as he called them familiarly, singing the praises of their commitment to promoting organ donation. Several patients and young recipients' families were present, including the Kumanos, who also appeared in the documentary. They spent most of the evening with the only guest in the room who eclipsed the two American sisters, MP Konō Taro, one of Liberal Democratic Party (LDP) men

behind the law's reform, and with whom Nakamichi-san and the Kumanos had worked closely in the negotiations leading up to the vote.

In this chapter I look at those events, and in particular at the patients' lobbying for the reform. Going back to the first instances of mobilisation by organ recipients in the 1990s, I discuss the emergence of health advocacy among Japanese transplant patients. I this way, I explore a not very well known case of patients' mobilisation in Japan, contributing to the growing debate on patients' advocacy and activism, and to the social analysis of the increasingly important role patients and their families play in the regulation and development of medical research and practice (Epstein 1995; Novas 2006; Rose 2007).

Through the life histories of both the first generation of patients and the families whose stories I have followed so far, I describe the unravelling of the public and political debate on transplant medicine in Japan that reignited the discussion on brain death and transplants more than two decades after the brain death problem (Lock 2002). The way in which the life trajectories of transplant recipients were interwoven with, and shaped, the regulation of this biotechnology sheds some new light on the political life and civil society of a country often described as static and antithetical to change. At the same time, it offers precious insights into the controversial issue of brain death and transplant.

# The First Japanese Transplant Recipients

> Transplantation can hardly be called a well-perfected medicine. It cannot be denied that, regardless of the development in immunosuppression, the spiral of rejection and infection is unavoidable. Nevertheless, if one thinks that life itself is the most precious thing (*hito no inochi ha nani yorimo tōtoi*), it is only human to want to prolong it just for the sake of being alive, even though one cannot recover full health (*kanzenna kenkō*).
>
> (*Noshi Rinchō* 1992: 31)

In 1992, the publication of the report of the Provisional Commission for the Study of Brain Death and Organ Transplant (*Rinji* N*ōshi Oyobi Zōki Ishoku ni Kansuru Chōsakai*), known by the acronym *Noshi Rinchō*, reignited public interest in the 'brain death problem'. After that, various committees tackled the issue of defining brain death. The Provisional Commission set up by the MHLW was charged to discuss the two related questions of whether brain death could be taken as human death, and whether organ procurement could be authorised from the brain dead (*Noshi Rinchō 1992*). The formation of the committee was taken as a sign that the government was considering the legalisation of organ donation from heart beating patients, and public and media attention was raised again around the 'brain death problem' (Lock 2002: 167-170).

"Brain death was everywhere," says Hasabe-san, who at the time was considering whether to list for a transplant overseas, despite the fact that the dominant opinion about the treatment in Japan was that it was both ethically problematic and clinically unsafe. As seen in Chapter 3, Hasabe-san went on to receive a transplant in the U.S.A., and once back in Japan became one of the few members of We Love Heart (WLH), a group for patients who had received heart transplants overseas (New Heart Club 1993). *Tokō ishoku* was a very exceptional practice, and WLH was born to foster peer-exchange among the few Japanese patients who had received a heart transplant, most of them in the UK, at a time when the operation was still legally impossible Japan. For Hasabe-san, WLH gave him the chance to be in touch with the wider community of Japanese transplant patients. He rapidly became one of the leading figures in the scene of transplant advocacy (Lock 2002: 175), and even though he had 'retired' from public activity after the passing of the law in 1997 he is still a well-known presence in the local transplant community.

His life-trajectory, from the hard-fought decision to list for a transplant overseas to the engagement with activism at home, can be taken as an instantiation of the emergence of transplant patients' organisations in Japan. After decades of dread clinical results, transplantation medicine had just recently entered a new phase of expansion following the development of a new generation of immunosuppressant drugs (Chapter 1), and on the back of these clinical successes in the field, the demand for organs materialised with

unprecedented urgency in Japan. New developments in the field of transplantation offered the prospect of a cure to patients, like Hasabe-san, suffering from otherwise untreatable diseases, but as his case shows, the acceptance of this treatment option was not without conflict. The social and clinical worth of transplantation was a controversial matter, and patients' groups became the privileged arena for the public validation of transplantation in the midst of the debate on brain death.

In some instances, transplantation became entrenched with already existent forms of patients' organisations. Associations formed by people suffering from kidney failure[65], heart conditions[66], or rare diseases like biliary artesia[67], for example, were all groups formed around the ideal of providing mutual support and guidance for patients with chronic disorders, and were transversally brought together by the shared hope that transplantation could offer a cure for a wide spectrum of disorders grouped under the label of organ failure.

In other cases, associations gathered together patients who had already received treatment, and were formed around the transplantation programmes in Japan that offered treatment through living-related and non-heart-beating donation. In an era when transplantation was not a well-established treatment and not all medical professionals would direct potential candidates to it, these groups functioned as a reference point for potential candidates and recipients. They provided guidance about doctors and medical centres that offered transplantation, and circulated practical information to advise patients who were pondering their treatment choices. These forms of sociality and peer-exchange among patients still play a crucial role in the life of recipients and their families (see Chapter 3), and at a time when surfing the web in search of information was not an option, and public accounts about transplantation rarely included the experience of recipients, they were the only reference point for prospective candidates and recipients. Patients' groups thus offered spaces for people to share knowledge useful for navigating post-operative life, through discussing

[65] Zenkoku iinz*ōbyō kyōgikai.*
[66] Zenkoku shinz*ōbyō no kodomo wo mamorukai.*
[67] Tand*ōheisashō no kodomo wo mamorukai.*

practical issues such as how to balance work life with care, whether or not to engage in physical activity as well as to what extent, and how, to manage information disclosure about their condition (Japan Transplant Recipients Organisation 1994).

Nakamichi-san joined one such group in the late 1980s, after he received a kidney transplant from a family member. A photographer from Osaka, Nakamichi-san considered himself lucky for being able to have the operation; not only did he have a suitable donor willing to help in his family, but he was also in care at one of the medical centres traditionally more proactive about transplantation which offered him the option of treatment and supported him through the screening process and the selection of the donor.

After he received the transplant, Nakamichi-san joined the hospital-based group for transplant recipients, and eventually took over the role of representative through what he described as a series of fortuitous circumstances (although knowing his character, I can guess that his decisiveness might have well played a role). He used his studio as a basis for the activities of the group, and taking advantage of his flexible schedule as a free-lancer he volunteered to organise events like the Transplant Games that aimed at bringing together a community of patients and healthcare professionals outside the closed circles of single transplant programmes. By making contact with other recipients' organisations around the country, Nakamichi-san's group developed into the nationwide association renamed JIA (Japan *Ishokusha* Association).

While JIA focused on Japanese recipients treated at home, the first associations dedicated to *tokō ishoku* were also formed in those early years. Ashida-san, the founder and leader of NIT Japan, lost his teenage daughter to biliary artesia in the early 1990s. With his wife, they had been members of a patients' group for families of young patients suffering from the disease, and after the loss of their daughter, they decided to fund their own association especially devoted to transplantation medicine (TRIO 2009).

NIT Japan started as the local branch of an international network of organ recipients originally established in the U.S.A., and over the years, it became a key point of reference for patients pursuing treatment overseas (see Chapters 2

and 4). NIT was also among the most active patients' groups on the transplant advocacy scene, promoting activities that brought together medical specialists and patients in planning the development of an efficient transplantation system. It was also actively involved in the mobilisation for the reform of the law, which in a way represented both the peak and the end of transplant advocacy.

The life trajectories of the people belonging to the first generation of Japanese recipients show how, during the years of the brain death problem, the first groups of *ishokusha* were formed to facilitate access to treatment and provide support to patients in a period when transplantation was mostly unavailable and highly controversial. The organisational goals and activities of these groups would become tightly intertwined with what interlocutors called the 'promotion of transplantation' (*ishoku wo suishin suru*), and through these networks patients and their families became closely involved in the public dispute on this treatment and with its legal regulation in the country.

## *ZōiRen*: Transplant Recipients Mobilise

> I had the chance to help my child, but there are a lot of people in Japan who can't receive the same sort of support we got. We were lucky, but many are not. Is it ok then to consider ourselves out of it just because we were lucky enough to make it through? I was really troubled by this. To me, transplantation should be possible in Japan. Japan is a developed country (*seishinkoku*); it should make this treatment available to its citizens, and to those of less affluent countries as well. When I joined WLH this was my spirit, but I realised quite soon that nobody cared too much. The more I attended their annual meetings, the more I grew uncomfortable (*iwakan*): I just couldn't see the point of a group of people, with the same disease, getting together once a year without any particular reason. I couldn't help but wonder: how can you be happy if one day you might need a second transplant? [Going overseas again] would be incredibly expensive, and it'd mean troubling others again (*meiwaku*). And besides that, lots of people die in Japan [because they cannot receive a transplant].
>
> (Komeno-san)

Komeno-san's son received a heart transplant in the U.S.A. in the mid-1990s. A friend introduced him to a family who had just returned from the U.S.A.

after an operation. Komeno-san's wife had seen the case of the young patient on TV, and through these connections, the family was put in touch with the patient's parents, who in turn referred them to Maeda-sensei. In a few months, Komeno-san raised the money, arranged contacts with the clinic overseas and left with his wife and son for the U.S.A.

After the successful intervention, they quickly returned to Japan, in the midst of the debate following the publication of the *Nōshi Rinchō*. Through a friend, Komeno-san joined WLH, but rapidly grew unsatisfied with the lack of political engagement of the association and begun to get interested in the emergent movement of transplant advocates.

The publication of *Nōshi Rinchō*, in 1992, was the catalyst for transplant advocacy. Patients of the first generation commonly talked of it as a milestone in the history of transplantation medicine in the country. In official accounts, it is often emphasised that the Commission failed to reach consensus over the question of whether or not brain death is human death, and even though it was officially intended to express a unanimous position, its final report appended a minority opinion arguing against the recognition of brain death (Lock 2002: 167-170). On the other hand, transplant patients usually noted that the report expressed an overall favourable position regarding the recognition of brain death, and lamented instead the conservative character of the ensuing law in the face of this initial validation of the new definition of death.

As I see it, the inconclusive result of the Commission's work significantly shaped the ensuing policy-making process, creating a precedent for legalising brain death for its practical functions in organ procurement while leaving it unsettled in the question of (re)defining human death (see below). At the same time, however, the actual implications of the *Nōshi Rinchō* went far beyond the content of the report. The issuing of the document engendered a sense of expectation about the imminent legalisation of organ donation from brain dead donors. In fact, in anticipation of the political vote that would finally open the way to transplantation medicine, in 1995 the national system of cornea and kidney sharing was reorganised into what is the current agency for organ procurement and allocation, the JOTNW. The *Nōshi Rinchō* represented in this sense a, thus far, unprecedented endorsement of the aims advocated by

transplant proponents, prompting the emergence of recipients' public mobilisation.

It is worth recalling here that health rights advocacy and patients' movements have a long history in Japan. In the 1970s, sufferers from the so-called Minamata disease, named after the town in southern Japan that experienced the outbreak, proved that the unknown disease was caused by environmental pollution in the area and managed to bring the owners of the local chemical factory to justice, obtaining both financial reimbursement and public recognition for the victims of the disaster (George 2001). The case set a well-known precedent of grass-roots movements in Japan, celebrated for its 'democratisation effects in mobilising public support and political protection for minority groups (*ibid.*).

After Minamata, the tainted blood case involving haemophiliac patients was probably the largest and most visible public health scandal in contemporary Japan, and this too saw the mobilisation of patients in defence of their rights. Haemophiliac patients who had contracted HIV/AIDS from blood tainted products formed patients' associations to provide mutual support to the sufferers of such a badly a stigmatised disease (Hirano 2008). Their experience grew into a social movement, which brought the leader, Ryūhei Kawada, to eventually be elected to parliament (Kingston 2004). The mobilisation of haemophiliac patients in the 1990s successfully focused public attention on the case and unveiled the complicity of political institutions, winning compensation from the government for its responsibility in the scandal (Feldman 2000). During the same years as the haemophilic patients' movement, people with leprosy also organised a lobby against the Japanese government, and not only did they manage to bring down long-standing discriminatory policies against leprosy patients, but they sued the government for financial compensation, obtaining an unprecedented legal victory against the state (Kingston 2004). Many features of these cases –in particular the strategic mobilisation of the media to attract public support, and the direct engagement with state institutions through forms of political lobbying– were to reoccur in the experience of transplant patients.

Notoriously, one of the instances of patients' mobilisation that intervened in an issue of particular public interest was the contestation of brain death by

advocates of disabled and neurologically impaired people (Feldman 2000; Lock 2002; see also Chapter 1). While their arguments against brain death had framed the public debate on organ donation for almost three decades since the Wada scandal, in the 1990s transplant advocates started to assert their claims in a more demanding and visible way, calling public attention to a cause that had so far been silenced in the general uproar against brain death.

In 1994, Liberal Democratic MP Nakayama Tarō submitted a draft of a law to legalise organ donation that equated brain death with human death (Nakayama 2011). The proposal immediately met strong antagonism in the Diet, but the debate on a law to enable organ procurement and transplant was effectively set in motion. The same year, JIA, WLH, and other patients' organisations joined efforts to advocate for the legalisation of brain death and funded the Network of Transplant Patients' Groups, or *ZōiRen* (*Zōki Ishoku Kanja Dantai Renkaku Kai*).[68] *ZōiRen* became the reference point for recipients' activism and for newly forged alliances between patients, medical professionals from the Japan Transplant Association and representatives of the political world like MP Nakayama Tarō.

*ZōiRen* epitomises the emergence of a new, politically charged form of mobilisation by transplant recipients. If the development of transplantation had always been a self-declared mission of recipients' groups, the social and political climate of the 1990s provided both the aims and language to bring this commitment to a whole new level. The political debate on the law raised public attention to the problem, while also offering patients a concrete goal to pursue in their cause to promote transplantation medicine in the country. Paradoxically, as I have discussed, the long awaited vote on such a law in 1997 created an impasse in transplantation and brought patients' mobilisation to a standstill.

[68] See the *ZōiRen* homepage at: http://www.isyoku.net/profile.html

## “A Traffic Light without the Road”

The vote on the Act on Organ Transplant (AOT) in 1997 was regarded by the people who advocated for it as a missed opportunity; in Ashida-san’s terms as “a traffic light without the road.” In the wave of the debate on brain death, the Japanese law fully took on the arguments advanced by patients’ rights advocates and legal scholars (see Chapter 1). As I have already noted, the law rejected the *uniform* definition of brain death as human death, meaning a position that equates the neurological diagnosis with the determination of death in *all* cases, regardless of a patient's or family’s will (Lock 2002: 111-116; Gervais 1986: 198-205). Instead, the AOT stipulated that brain death was to be considered as equivalent to human death only in cases of organ donation (Lock 2002: 178-183).

The problem Japanese legislators were faced with was how to legalise brain death organ donation as a form of cadaveric donation while respecting the ‘dead donor rule’, which dictates that the patient must be deceased at the time of organ procurement, without going to the lengths of giving a statutory definition of human death as brain death, which would have enabled the lawful withdrawal of life-support treatment from patients at physicians’ judgement. In other words, how to define brain death as human death without defining human death as brain death. Of the various possibilities considered, including that of leaving the definition of death to individual choice, and to suspend the legal definition of murder in the case of organ procurement, the solution was eventually chosen of limiting the legal validity of the neurological criterion of human death to cases of donation, when the patients and their family had explicitly consented to the person being declared dead in order to procure organs (cf. *Nōshi Rinchō* 1992: 9).

As discussed in Chapter 1, the corollary of this policy was that patients needed be registered as organ donors to be pronounced legally brain dead. The use of donor cards thus became a necessary condition to enable organ procurement. Further, families were given the right to overturn the patient’s decision, practically introducing a double system of consent to organ donation. To request families’ consent is, in fact, common practice, under policies that

take the patient's will as sufficient condition for organ donation. In Japan, however, since physicians were not bound to demand consent for organ donation and usually left the initiative of broaching the issue to the family (Lock 2002), the next of kin would practically find themselves in the condition of having to request, rather than consent to, organ donation (see more in Chapter 6). Finally, because the donor card became to all intents and purposes a legally valid document for deliberate end-of-life decisions, patients under the age limit for legal consent were automatically excluded from organ donation, producing the impasse for paediatric transplantation the effects of which I have described.

In this way, the AOT imposed particularly strict regulations on a system that was not even in place, while little effort was made to implement an efficient system for organ sharing. The newly created JOTNW remained poorly funded, and run by bureaucrats that Nakamichi-san described as parachuted in (*amakudari*) from the MHLW. They had no direct interest in the development of transplantation, and no knowledge of the critical nodes to solve (diffuse presence of coordinators, collaboration with the medical staff, etc.) to create an efficient system for organ procurement.

The law, however, was meant as a temporary solution and was due for revision in three years time. Counting on this, recipients' organisations carried on with their public mobilisation aimed at promoting social awareness on organ donation and appealing for the reform of the law. They run seminars and public events like the traditional Ginza parade that marched through the streets of central Tokyo ending with a sit-in in front of the MHLW every year. These events also served to distribute donor cards, which were now the very practical means to enable organ donation. In fact, refitting the public collection points at convenience stores and post offices became almost a symbolic gesture of contribution to the cause of transplant advocacy. Patients' groups also organised various petitions to the government, and every year staged a public ceremony to officially submit them to the MHLW.

> We did these activities, like distributing the cards, but it's not that the more cards we distributed the more donations we had. We also collected a lot of signatures on our petitions. We went on for years; I think that just my family and I collected alone around 10,000

> signatures. I even included the petition in my *nengajō* [New Year's Greetings Card]. People were often responsive. Overall with *ZōiRen* we managed to put together 40,000/50,000 signatures. It's a lot of work. And what was the result? Nothing. At the beginning I thought that if we could show all those petitions as a proof of people's support, the government would hear us and do something. But that's not what happened, and I realised that no matter what we did we would get nowhere. Every year we attended a meeting, in autumn, at the MHLW. They are those who should be interested in organ transplantation, but in fact they just follow the policy and don't consider anything outside of it, so obviously they had no interest in reforming the law. But that's what we wanted; that's what we thought was needed: to change that law, to make it similar to international policy, to make it in line with the WHO indications. But they had no interest in that. I thought the aim of the MHLW was to protect the lives of citizens, and that given that lives were put at risk during the enterprise of going overseas, they would have shown some concern about the problem. But they didn't feel this was their mission (*shimeikan*). Just to give you an example, [under the old system] if people didn't have a donor card they couldn't donate, but it's difficult for everyone to get a card. So I proposed that instead of distributing cards, it'd be more effective to print the consent form on the back of the national insurance card, so that everyone would automatically have it […] They told me that the space on the back of the card was for everyone to use as they wanted; some people, they said, use it for personal pictures. I was so pissed off […] And now you see where it is? On the back of the national insurance card.
>
> (Komeno-san)

The vote on the law had spelled the end of the public debate on brain death and transplantation. The effects of the policy remained largely unknown to the general public and politicians alike, and, despite its efforts, *ZōiRen* hardly had the means to mobilise a large grass-roots movement or raise public interest towards a problem that was considered to have been solved. On the other hand, politically influential groups, such as the Paediatric Association and the Japan Bar Association, remained firmly against the full legalisation of the new criterion of death, and the media were so alert to the problem that every single case of organ donation from a brain dead donor was reported in the news. Brain death was still a sensitive enough issue that not many politicians wanted to tackle it, for fear of compromising their reputation, and given the lack of political interest and public pressure, the plan of revising the reform was effectively abandoned (Nakayama 2011; see also Lock 2002).

The approval of the law created in many ways a situation worse than the one it was supposed to solve, while also revealing the shortcomings of patients' advocacy. Patients' commitment to promoting social awareness, for example by distributing donor cards and running public events, had no effective impact on the bureaucratic and logistic conditions constraining organ procurement on a structural level. At the same time, patients' request of a revision of the law, in the form of public petition, fell on deaf ears.

## Creating Consensus, Making Problems

> A Parliamentary commission was formed to examine the law's revision. It seemed that things were moving on a bit, but in fact nothing happened. One day, we were called to one of their hearings to give evidence on the state of transplantation medicine in the country […] During the Q&A session, I took the chance to ask them […] how long would it take to move from the discussion to some concrete initiative (*jitsugen shiō*). MP Nakayama Tarō had listened attentively throughout and at that point he intervened:
> "In all honesty," he said "the reform is actually impossible. There's no real chance we can make it."
> When the law was voted on in 1997, he explained, there was a massive debate and the so-called brain death problem (*nōshi mondai*) was everywhere on the news. The issue of brain death was on everybody's lips and transplantation was brought to the centre of public attention (*yō no naka ni chūmoku*). A heated debate mounted over the topic (*sanzanna giron ga moriagatta*), so that it was a good time to sit down and discuss a solution to the problem. But what about, then, in 2003? There was no such debate and the issue was no longer of interest to those in political power (*seiken no kanshin*). And as long as it was not on the political agenda, there was little to do.
>
> (Komeno-san)

Like Komeno-san describes, in the years that led to the vote of the 1997 law, and in particular after the *Nōshi Rinchō*, the attention of the general public had been constantly alerted to the brain death problem. Whether because of the intense media coverage of the problem, or by way of famous intellectuals' intervention on the debate, or again through the wide body of popular literature published on the topic, including titles like 'Brain Death' by Tachibana Takashi

(1986) that sold several millions copies, the average Japanese citizen could hardly be oblivious of brain death, and of the fact that it was a 'problem' (*nōshi mondai*).

Especially with the political debate on the law, as the attention shifted from the problem to the solution, the dominating framework of interpretation of the debate has been that of 'consensus'. Strictly speaking, the approval of a law wasn't a pre-requisite for authorising transplantation medicine. In the majority of countries, the development of transplantation medicine updates the promulgation of legal statutes on brain death; in some instances, then, brain death is regulated only through medical protocol and was never defined in law, as in the UK, which has no statutory definition of death (Widjiks 2011). In Japan too, the famous Wada case happened in fact before the enforcement of a legal or ethical regulatory framework, and even during the years when the country was grappling with the 'brain death' problem, cases of organ procurement from neurologically injured patients were reported, causing scandal and further uproar[69]. The public controversy over the definition of death made the vote on a law necessary, while the increased availability of transplantation medicine abroad had made the dilemma impossible to ignore. Before being a solution to the problem, then, the law was a way of identifying a specific form of problem; one that was explicitly framed as a political issue, in the sense that it bore repercussions on both individual and collective forms of life.

From this perspective, the public relevance of the policy-making process in Japan is indicative of the increasingly crucial role that legal institutions play in the regulation of medical research, practice, and technology (Jasanoff 1997). As biotechnologies open the way to the reconfiguration of boundaries, such as those between life and death, which were once at the very foundation of the legal discourse, society, it seems, has made explicit to itself the role that the law and public policies play as active actors in the fabrication of life itself (Teubner 1989; Pottage 1998; Pottage and Mundy 2004). The debate on the AOT and its

[69] The 'Handai case' remains particularly famous. In 1990, after the Japanese Medical Association had ratified the criteria for the determination of brain death in clinical practice, surgeons of the University of Osaka (known as Handai university), traditionally very proactive about transplantation, authorised cases of organ procurement from brain dead patients. A police investigation was launched into the episode, which was also widely reported in the media (Lock 2002: 162).

reform was, in this sense, a sort of meta-reflection on the process of social construction of death in Japan.

As recommended by the *Nōshi Rinchō*, the question of whether or not brain death is human death couldn't be solved by ratifying the decision of medical experts, but needed to be deliberated through a process that reflected 'social consensus' (*shakai gōi*) (*Nōshi Rinchō* 1992). Bai Kōichi put forth a similar point in commenting the on the report with which the Japanese Medical Association had ratified the criteria of brain death, stressing that these could not be applied in practice before society had reached a consensus over the definition of death (quoted in Feldman 2000: 96). Lock too, drawing on Japanese media, describes the process of deliberation of the law on brain death and transplants as one aimed at "reaching public consensus" (2002: 177-78). Indeed, the trope of consensus became the accepted reading of the problem, to the point that MP Nakayama even titled his memorial about the two-decades long process of political negotiation on brain death 'Medicine in Search of Popular Consensus' (*Kokuminteki Gōi Mezashita Iryō* ) (2011).

Consensus is a value-laden term, especially when it comes to Japan. The organisational basis of Japanese society, the argument goes, is the person's role within the collective, rather his/her individual identity (Nakane 1970). Decisions, therefore, are deliberated within the group, often through laborious and lengthy negotiations, which don't involve the straightforward assertion of individual claims but aim instead at reaching a unanimous resolution that everyone has come to agree with (cf. Krauss, Rohlen and Steinhoff 1984). Social research on Japan has thus traditionally emphasised that harmony (*wa*) is one of the main pillars of Japanese social life (Nakane 1970). The Japanese are said, and sometimes say of themselves, to be particularly loyal to the group and acceptant of decisions taken in the interest of the larger collective, an attitude that explains the high degree of social stability in the country and even its economic productiveness (cf. Vogel 1979). On a political level, this translates into the idea of an amicably authoritarian society, where decisions are taken by a ruling elite and internalised through mechanisms of social persuasion or pressure more than imposed by means of coercion (Sugimoto 2003). Publicly questioning authority is regarded as problematic in Japan, for it would put one

in a vulnerable and culpable position. The Japanese are therefore represented as deferential to power or disinterested in politics, and civic involvement in public decision is said to be scarce, with civil society organisations counting on a limited grass-roots support (Pekkanen 2006). This, in turn, is reflected in the common representation of Japanese professional politics, considered authoritarian and conservative. Indeed, while government turnovers are frequent in Japan, the national conservative party, the Liberal Democratic Party (*Jimintō*) is one of the world's most consistent political parties and has been in power almost continuously since 1955. Furthermore, while the constitution formally defines the elected Diet, composed of Upper and Lower Houses, as the highest decision-making body, in reality, it is commonly acknowledged that power is in the hands of a small elite of Ministry bureaucrats (Mc Veigh 1998).

The frame of consensus thus depicts Japanese polity, and professional politics in particular, as static and refractory to change. Consensus, however, exists only insofar as conflict does, as Schwartz argues through the study of interest groups' negotiating in political decisions in Japan (1991). Indeed, as Komeno-san's story suggests, the engine of public decision seems to be not social consensus but social conflict.

Feldman counters the assumption that the scarce recourse to litigation in Japan is indicative of the fact that people favour modes of resolution of conflict based on mutual consensus over the open contention of individual rights (2000). Through cases of public mobilisation of minority groups, including patients' rights activists against brain death, Feldman argues that people make different uses of legal institutions to assert their claims and promote their interests, and that in these instances social conflict is brought to the forefront not by means of litigation in court but through trying to influence policy-making (*idem*). Feldman's argument thus highlights public policy as a site where conflict is identified and strategically managed; the implication of this, as his focus of the contestation of brain death shows in light of the present discussion, is that policies are also a site of change.

## “One by One”: the Transplant Recipients’ Lobby

> Long story short, at the meeting [with MP Nakayama Tarō] we were told that the reform was impossible. And in fact, it seemed hard […] We’d been doing the parade, and the petition, and so on; we’d run out of options. What was left to try? […] One thing was sure: we’d got nowhere going on like that […] Nakayama Tarō said it was impossible to change the law because there was no public interest in the issue of transplantation, but I thought that if MPs themselves had some interest in the first place, then maybe we could have a chance. In the end, it’s MPs who reform laws. So I checked things out: there are seven hundred and twenty two MPs in the Diet. Not thousands; seven hundred and twenty two. I thought I could try and talk to them, one by one.
>
> (Komeno-san)

In 1997, the same year the law on transplants was voted in, Komeno-san quit his job at a company based in Tokyo after his department was downsized, and started up his own business in his hometown. The business was thriving at the beginning, but being self-employed Komeno-san had the flexibility and time that few *salarymen* can enjoy. After the successful campaign for the vote, Hasabe-san decided to ‘retire’ from his political activity, Komeno-san took his place in the *ZōiRen* as representative of WLH and began to volunteer with the group.

The AOT was due for revision in 2000, but given the general political disinterest, the plan of a reform never took off and the patients’ movement was losing its momentum. A sign of change seemed to come in 2003, when the problem of transplantation touched the world of professional politics at its highest ranks. In 2003, LDP MP Kōno Tarō donated part of his liver to his father Konō Yōhei, then chairman of the House of Representatives. The episode started the collaboration between the younger Kano and his older colleague in the LPD, Nakayama Tarō, the man behind the first bill of law to legalise brain death that the Konō had voted down years before (Nakayama 2011). In 2003, then, MP Konō submitted a bill of reform, named the Konō Bill, and this for the first time opened the way to a possible revision of the AOT, but the process of deliberation (*shingi*) was repeatedly delayed and the plan seemed to fall through.

In the summer of 2004, Komeno-san booked private appointments with some MPs to discuss with them the contents of the Kono Bill. During his two-weeks break from work, he arranged to see as many MPs as he could, and reported back to the *ZōiRen* group to keep them updated about the contents of these meetings. While still working on public initiatives to raise awareness of organ donation, from the autumn of that year, Komeno-san and others concentrated their efforts on the activity of lobbying (*roobi katudō*) inside the Diet.

The new strategy best suited the political dynamics underpinning the problem. Differently from the majority of laws approved in Japan, which are initiated by the Cabinet, The Act on Organ Transplant was an Act of Parliament (*giinrippō*). Because laws submitted by the Cabinet are notoriously prioritised over *giinrippō*, keeping the problem on the agenda of individual MPs was essential to avoid having the discussion on the reform postponed indefinitely.

Furthermore, even though *ZōiRen* could count on influential allies in the LPD, which at the time was the majority party in the Diet, political affiliation was a poor predictor of the actual support for reform. The approval of the AOT in 1997 had set the precedent of a conscience vote, and in fact the distribution of votes in support of or against the reform was at a tangent to political connections and relatively independent of party directives (with the sole exception of the Communist Party which strongly opposed brain death). A few were particularly outspoken and had been engaged with the issue for several years, like MP Nakayama Tarō or Abe Tomoko, a paediatrician elected as a Social Democratic Party member, who had been at the front line of the opposition to brain death in the parliamentary commission on health and welfare charged with examining the reform. These cases aside, however, the majority of the MPs had no clear position on the problem, giving considerable leeway to the *ZōiRen* to win the support of enough members of the Diet to reach a majority of votes.

This strategy, in turn, was well adapted to the composition of the group. As an interest group, the *ZōiRen* lacked the political leverage of big groups that traditionally exercised an influential role on the Ministries (Mc Veigh 1998). As representative of a minority group with no financial or corporate interests, the

*ZōiRen* could only benefit from a situation that offered them the space to talk to individual MPs about their plan "one by one", for they arguably lacked the power of mobilising the MHLW or the Cabinet.

At the same time, Komeno-san and the others couldn't count on grass-roots support either. The group was founded as a platform for devising a common agenda and coordinating the organisation of work across six different patients' groups. Every group officially had a spokesperson, who was supposed to act as a point of contact between the *ZōiRen* and its base, but in fact information exchange and grassroots participation was always rare. In practice, behind the pompous name of *ZōiRen* were a few middle-aged men and an 'old lady'. Kanemaru-san, officially the representative of an association in support of children with heart conditions, had been involved in the issue of transplantation for several years, and as seen, she had been a point of reference for many families pursuing a transplant overseas (see Chapter 2). Shimada-san came from a group for families of children with biliary artesia. The leader of the *ZōiRen*, then, was Nakamichi-san, who over his years with the JIA had made useful connections in the political and medical world, particularly with the Japan Transplant Association. The alliance with the professional organisation of transplant surgeons was used to maximise the political impact of the patients' advocacy, drawing upon the political influence of well-known professors, like Endo-sensei, as distinctive members of various constituencies.

Komeno-san and the others usually met once a month in some cafe in Tokyo, when Nakamichi-san was in town to make contacts for the lobbying process. For the rest of the time, they mostly kept in touch via email, updating each other with feedback from their meetings. They used a chart to keep track of the negotiations, in which next to the MPs' names, they inserted codified symbols to mark the politicians' degree of support for the various plans of reform, such as a double circle indicating strong support, a single circle for opposition. This system gave them a practical tool to organise their efforts and map the on-going changes in the Diet. This new strategy focused on political lobbying gave transplant recipients the outlet, goals and means to greatly improve the incisiveness of their action, and the *ZōiRen* effectively reconfigured as a new interest group. Illustrating the composition of interest groups in Japan,

Sugimoto argues that a new wave of civil organisations have emerged since the mid-1990s that press for fresh values of social justice in various sectors, including welfare (2003: 286). While traditional interest groups representing corporate and professional organisations are known to operate through connections with the Ministries, these more recent groups are usually oriented towards the Parliament, and in some instances they pursue lobbying activities (*idem*). This was, indeed, the aspect Nakamichi-san and his friends were arguably more proud of as they talked of how they managed to bring an issue that was of interest only to a minority of people to the attention of the highest ranks of professional politics.

## Transplant Advocacy: Returning and Requesting Favours

The composition of *ZōiRen*, the scarcity of grassroots involvement, as well as the tack they took in lobbying for reform are all are revealing of the social dynamics specific to transplant advocacy. In most cases, transplant advocacy is not directly related to the hope of improving one's own condition (cf. Novas 2006), but rather takes the form of being a legacy of one's past medical history. In the majority of cases, people are drawn to advocacy after they have already received a transplant, or assisted a family member in the process. Even when advocacy is linked to hope of a future cure, patients normally become involved with the issue of transplantation when this concretely materialises as a treatment option, but at this stage, when they are eligible for the operation, people are often too sick to practically engage in the activities of patients' groups and too concerned with the management of care to even entertain the idea of advocating for the promotion of organ donation. In practice, underlying transplant advocacy is the hope that *others* will benefit from it. In this sense, people described their commitment to the promotion of transplantation as a form of *ongaeshi*.

*Ongaeshi* means to return a favour. As I only touched on in my Introduction, transactions of *on* (debt of gratitude), and the dynamics of reciprocity and indebtedness they bring about, have been described as the

fundamental moral principles underlying social interactions in Japan (Benedict 1954; Lebra 1976; Befu 1968; Rupp 2006). *On* expresses a transaction between a favour granted as an act of benevolence, independent of the social obligation to give (known as *giri*/*gimu*), and the gratitude and indebtedness incurred in receiving it. It implies the obligation to reciprocate the favour received, and therefore translates into a positive sense of gratitude but also into a feeling of indebtedness. Lebra, for example, describes that the recipient of *on* is expected to feel, and does actually feel, grateful for the favour received, expressing appreciation, thankfulness (*arigatō*) and deep gratefulness (*kansha*) for it (1976: 96). At the same time, receiving an *on* means to contract a debt, and the favour imposes a burden on the recipient, which Lebra says is expressed by the double idea of *arigata-meiwaku* (gratitude-imposing nuisance) (176: 97).

English literature about organ and tissue donation often focuses on the metaphor of the gift. Usually, North American anthropologists argue that the trope of the gift is conceptually 'fallacious' and detrimental, because it imposes a sense of obligation on patients and their families (Fox and Swazey 1978; Siminoff 1999). They have pointed out that the gift conceals the sacrifice of the donor (Scheper-Hughes 2000), and therefore 'mystifies' the relationship at stake (Sharp 1995; 2006) and even functions as a form of 'ideological antirejection' against the concerns over the use of the human body as a therapeutic resource (Joralemon 1995). While highlighting important issues, it seems to me that these interpretations reiterate a specific theory of gift-exchange and reciprocity that is illustrative of the anthropological intellectual tradition on the theme (cf. Mauss 1970) more than it is descriptive of people's practice in real life. As Rupp argues of gift-giving in Japan, recent anthropological writing explores only a small part of Mauss' thinking, the idea that the gift was part of the donor, has been "blown out of proportion", and a more general line of argument of his work has remained untested:

> The action of giving itself is an instantiation not so much of a particular person or self, but of the social relationship between giver and recipient. It is not primarily that that the gift as an object stands

> for the giver's identity. Rather, it is a material embodiment of a social and cosmic order
>
> (2003: 197)

The way in which Japanese recipients spoke of their experience in terms of *ongaeshi* gives a subtle and complex account of the social order that transactions in human organs shape.

*Ongaeshi* conveys gratitude towards the individual donor, and for Japanese patients, similarly to North American recipients, this is often linked to the responsibility of being compliant with medical care (see Chapter 3, cf. Siminoff 1999). Adult patients, then, described the responsibility of managing the post-operative care as a form of *ongaeshi* towards the donor, construing indebtedness in terms of making the most and taking care (*taisetsu ni suru*) of the gift received (Yamazaki 2009). This focus on the positive connotation of *ongaeshi* relieves the recipient of the burden that comes with a gift that is impossible to reciprocate (cf. Sharp 2006; Fox and Swazey 1978), redirecting the indebtedness of the donor towards the care of oneself.

> The presence of the donor was always in my mind. A transplant, especially of the heart, means someone had died [for me to receive]. I couldn't help but ask myself why that person is no longer alive whereas I am. Does my life have any meaning? Am I person whose life has any particular value? Then I started to think about the feelings of the [donor's] family as they lost their loved one. What kind of thoughts could they have when they decided to donate? When I was in high school, I thought a lot about these things; about how to come to terms with the fact that death was part of the life I was given to live (jibun ga ikiteiru jujitsu no naka no shi wo dō *mukiatte ikeba ii no ka*). […] Then a friend of mine asked me: "Why don't you just forgive yourself? (*yurushiteageru*)". It made a strong impact on me: I'd been the one who put such a burden on myself. I never allowed myself to just live. I'd taken upon myself all that suffering, and questioned the worth of my own life. My mom told me they did it just because they wanted to help me; they wanted me to live. It was not about causing someone's else suffering or waiting for someone's else death; they did it because they wanted me to live. But maybe all the pressure I put on myself was the other side of this will to live. Once I realised this I became very positive towards what I'd been given: the time I was given, the life I was given, and obviously the heart I was given. I think that's part of the person I have become, and that was my way of giving back (*ongaeshi*)
>
> (Nagahisa Midori)

In another sense, *ongaeshi* redirects patients' gratitude towards others. As Natsuko explained to me, *ongaeshi* is the moral obligation to give back to someone one has received a favour from, but since this direct reciprocity is not possible in the case of transplant, one has to give back to others. People thus framed advocacy through the idea of *ongaeshi*, arguing that transplant recipients have a special moral obligation to give back to society. This conception of *ongaeshi*, as the responsibility of taking care of oneself and giving back to others, is tightly intertwined with the idea that being a transplant recipient (*ishokusha*) entails the responsibility of being compliant with care but also of leading an active and independent life as a contributing member of society, and it is indicative of the forms of sociality through which people negotiate their subjectivity as *ishokusha* (see Chapter 3) are also considered occasions to practice *ongaeshi*. Being involved in seminars and educational campaigns, giving testimony to the 'greatness of transplantation', attending events like Maeda-sensei's seminars or JASOT charity concerts, and helping out with other patients' fundraisings are normally decried as ways in which people can give back to society for what they have received.

Parents of young patients often took upon themselves the burden of reciprocating the favour, as a way of protecting the children from experiences like the one Nagahisa-san describes. In their life trajectories, then, the idea of giving back overlaps with making a meaningful legacy out of their experience. For people like Natsuko and Yuka, who lost their child, contributing to the development of a treatment their loved ones couldn't benefit from, represented a way of keeping their memory alive. Both the women described their involvement in the promotion of transplant as the legacy of what their sons had endured. Advocacy was to them a way to give meaning to their son's experience, which in this way continued to live on and would help others almost as if the children had become organ donors.

More generally, for the people who pursued or received a transplant overseas, giving back was considered particularly important in light of the exceptional help they received. If Lebra writes that bestowing a favour that binds the recipient can impose a burden (*meiwaku*), the ethnography above describes how *meiwaku* also comes from asking for favours one doesn't feel

entitled too (see Chapter 4). It is precisely because asking for favours puts people in a precarious position, that *ongaeshi* becomes a powerful moral justification of advocacy. In a society like Japan, where a strong assertion of individual needs and aggressive lobbying can be counterproductive ways to express one's claims, *ongaeshi* becomes an effective concept through which to mobilise advocacy.

> The first responsibility of a transplanted person (*ishokusha*) is to fulfil their life (*inochi wo mattō suru*) without wasting what they have received (*itadaita mono*). For example, one has to take care of oneself (*jiōk kanri*), avoid getting ill, and do what you can to stay healthy and so that the organ can live long, and you can live long too. That's a first, big responsibility (*sekinin*); a responsibility towards the donor. But then there's another one. It might not be an important issue in America or Europe, but in Japan being able to receive an organ, whether it is from a living or a deceased donor, is very special (*tokushū*). The probabilities are not very high […] It's very rare, really very rare. It might be the wrong way to put it, but it's like being chosen (*erabareteiru ningen*). You might say chosen by God, I don't know, but certainly it's a matter of luck (*kōun*). You cannot make it happen by yourself; even if you want to receive [an organ] you cannot make it on your own. In this sense, I really think we're lucky people (*kōnna hitotachi*). And as lucky people, we do have a responsibility to return to society the favour (*onkei*) we have received. I think that transplant recipients must (*subeki*) actively engage in making transplantation more available, for example by showing how receiving a transplant helped them becoming healthy again, so that they can make [this treatment] more appealing. I think it's really up to us to take charge of this (*shinakucha ikenai*), because we're very few […] It's not just a wish (*shitehoshii*), I really think we must do it (*subeki da*).
>
> (Nakamichi-san)

Nakamichi-san, however, is not representative of the majority of transplant recipients in the way he turned advocacy into a full time job. Transplant advocacy is profoundly different from other instances of patients' activism, such as the classic example of HIV/AIDS (Epstein 1993), or the most recent case of autism, or chronic diseases in which the re-claiming of one's identity as a person affected by a disease is construed as empowering (Orsini and Smith 2010; Rabehariosa 201). For transplant recipients, on the other hand, overcoming the difference between one's medical condition and a state of

'normality' is central to the negotiation of treatment efficacy (see Chapter 3). It isn't surprising, therefore, that the *ZōiRen* had so little grass-roots support.

The emergence of patients' advocacy arguably gave space to transplant recipients, especially those of the first generation, to overcome the social stigma attached to the disease and the decision of pursuing such a contested treatment (see Tomomatsu 2013; cf. Hirano 2008). At the same time, however, there are significant limits to how transplant advocates can articulate their claims in the public arena. While forms of so-called 'biological citizenship' often articulate citizens' quests for assistance from the state, through the language of 'health rights' (Petryna 2002; Biehl 2003), transplant advocacy calls attention to needs that depend on the rights of other citizens (the brain dead persons). Like the fundraising, then, transplant advocacy cannot take the form of a claim to rights, but is about mobilising favours through mutual moral obligations.

## Asking for Help Once Again

> During the campaign for Shuichi I was never able to join the street fundraising. [He was very ill] so we decided that I'd stay with him at the hospital while my husband would take care of the street fundraising. For this reason, even now when there's some new fundraising campaign I absolutely don't take part in it. I feel bad doing street fundraising for other children when I couldn't do it for Shuichi. I feel like I'm betraying him (*Shuichi ni taisuru mōshiwakenai*). The Satos for example often help out with the street fundraising for other patients, but I absolutely don't do that... In a way, I had the same feeling about going on the street (*gaitō*) again for the petition [to reform the law]. On the other hand, though, I thought that changing that law could help children like Shuichi. Maybe if we had had the chance of receiving the transplant in Japan, he would have survived, because the travel itself causes lots of stress and can be really debilitating for the children. That's also what happened recently with Mai-chan, I think you know. For Shuichi it was the same [his condition deteriorated badly soon after arriving in the U.S.A.]. So even if just to spare patients this further obstacle, changing the law would be worthy. On the other hand, though, making transplantation available in Japan could also mean making it impossible to go overseas. Take [Sato] Aya-chan, for example. She had RCM and she was in very good condition when she left for the Sates. She was able to walk and move, and even once she got there she spent most of the [waiting] time in a private residence [not at the hospital]. I'm not saying it was a fun trip, but at least she was not on a respirator

and she didn't need intensive care. For kids in such a condition going abroad can be the best choice, and at the time [when the Satos went to the U.S.A.] they could do so because in Japan it was completely impossible. In fact, when kids are enough to be eligible for the transplant but they are in a stable enough condition to undergo the travel overseas, then going abroad can be a better choice than waiting in Japan. So, in that sense, to change the law could well mean to destroy their chances (*kodomo no mirai wo nakusu*). By changing the law we could have a situation where there were no donations, and in the meantime children [would die who] might have benefitted from going abroad. Maybe not children with DCM, maybe they wouldn't make it anyway; but at least patients with RCM could have been helped. And in fact it's been like that in a sense; I mean, for a while there were no donations at all, only now there's been the first (case of a paediatric donor). So in a way, we could end up with reforming the law only to make the situation of children even worse (*chansu ga nakusaseru hōritsu ni naru kamoshirenai*). In the end, however, even though it could turn out to be bad for some, I personally believe that transplantation has to be made available in Japan. Anyway, I was still not very happy about the street petition! I talked with a friend of mine. She's a friend of mine who also lost her son [to *tokō ishoku*], and we're still very close today. When her son got ill she contacted Ashida-san, but the child died before they could start raising the money, so now, she said, she wanted to do something. Well, in a way, she was in the opposite situation to mine. She could do nothing to try and help her child: she couldn't do the street fundraising, she couldn't try to receive the transplant, nothing. So now she wanted at least to contribute to the petition. It's a weird way to put it, but I felt like I kind of owed it to her. If she missed this chance, she'd never have another occasion to do something for her child (*kodomo no tame ni yatteageru koto ga nai mama ni icchau*). And I know how bad that can be. So I was like:
"Ok, let's do it together!"
And that's basically how it went. For three days we went about collecting signatures for the petition (*shoumei katsudou*) in front of the [big department store] Takashiyama. [She laughs]. We were going around and asking for help [*onegai shimasu to iu*]. The initiative was reported in the news, and Endo-sensei also asked for the collaboration of others of his patients. We collected more than 30,000 signatures; we didn't think we'd get that many. We contacted all the people who helped with the Rescue Groups and the street fundraising, and I posted the advert on internet [on my blog]. Through that we managed to get some other 8,000 signatures. It was a lot as if you think we had to do it all in one month [to meet the schedule of the vote at the Diet]. Then we submitted the petition and we held a press conference. Eventually, the reform was voted in, and for me that wouldn't have been possible without going through all that we went through. We did the fundraising and he died, and if I hadn't experienced that failure, if I hadn't had the feeling that

> something had to be done, that I needed to give back something to society (*shakai ni ongaeshi*), well, I don't think I would have done it.
>
> (Kumano Natsuko)

## The Plight of *Tokō Ishoku* Children: from Minority issue to Social Problem

In February 2009, Fujita-san, the former leader of the rescue group for Shuichi, contacted the Kumanos to ask for their help with the petition he was organising to support the law's reform. Shuichi died in the last days of 2008, and Natsuko and Keisuke had just returned to Japan at the peak of the debate on the reform. After years of delays, the vote seemed imminent at last, and the issue of *tokō ishoku* became that which moved the Diet and once again mobilised public interest about transplants.

With the help of Ashida-san, who was in touch with numerous *tokō ishoku* patients, *ZōiRen* organised a series of press conferences with families of young patients who had travelled overseas for transplants, including the bereaved parents of those who didn't make it back home (*kizoku*). These press conferences were intended to be an opportunity for the bereaved families of *tokō ishoku* patients to directly address MPs about the reform as part of the activities run by *ZōiRen.* They were usually held at the MHLW, and became a strategically important weapon to mobilise public attention through the Ministry's *kisha kurabu*. The *kisha kurabu* are a news corps based at the Ministry, and as with the press conferences that launch the fundraising campaigns, relying on these connections with the media establishment ensured wide coverage for the patients' campaign. Journalists based at MHL who were reporting on the on-going parliamentary activities concerning the reform, started to pick up on the problem of *tokō ishoku*, and in this way, the plight of young patients travelling overseas for a transplant became tightly entrenched in the debate on the law and the ideological controversy of brain death.

The issuing of the Istanbul Declaration and the updated WHO principles on organ procurement, in 2008 and 2009 respectively, also played a crucial role

in upholding the public prominence of *tokō ishoku.* In 2008, MP Nakayama Tarō even organised for the WHO representative Luc Noel to give a speech at the Japanese Diet addressing the issue of self-sufficiency in organ procurement (Nakayama 2011), and in the months leading up to the vote, the constant reference to the changed international situation became a distinctive feature in media reports on the reform.

International statistics about organ donation rates started to appear regularly in the media, together with data about how many Japanese patients travelled abroad, how many candidates were dying on the waiting lists and how few had received transplants in more than ten years since the legalisation of brain death in Japan. On the other hand, the almost obsessive mention of the new WHO guidelines (which in fact had no binding power) presented a scenario where even the last resort of a transplant overseas would be made effectively impossible. Equally problematically, it raised the fear of international criticism (*kokusaitekina hihan*) of Japan, by hinting at the fact that the situation would eventually become "unsustainable on the global stage".[70] In fact, in Japan the WHO recommendation for self-sufficiency was most usually discussed in terms of "self-restraint" (*jishuku*), clearly pointing to the problem of *tokō ishoku* (Yomiuri 2009a).

Casting the national debate, traditionally framed around the issue of brain death, against the background of the global crisis of organ shortage, these discourses mobilised the perception of (presumed) implications concerning the international reputation of Japan. At the same time, the comparison with foreign countries, which at the time of the 'brain death problem' in the 1990s was framed around cultural differences in order to legitimise the Japanese position against the new death, now became a matter of statistics on organ donation rates, thus manifesting the local shortage of organs as a new social problem (Yamazaki 2013).

The evolving international situation created a sort of moral panic, which, amplified by the media, contributed greatly to inform the public debate on the reform (Pharr and Krauss 1996). In particular between 2008 and 2009, the

[70] From the Fuji TV documentary *Dōshite Susumanai ka: Nihon no Zōki Ishoku'* (Organ Transplantation in Japan: Why It Never Developed?).

cases of young patients travelling overseas for transplants caught the media's attention in a way that far outstripped the usual coverage accompanying the launch of new fundraising. After the press conference to announce the campaign for Maki, in 2008, Arai-san was contacted by two different national TV agencies about a documentary on his daughter's case. The reportage, realised with Fuji TV, followed Arai-san during the fundraising up to Maki's departure for the U.S.A. The programme, which also featured a brief interview with MP Konō Tarō, presented data about the broader situation of patients going abroad (or dying trying), and ultimately asked why transplantation was not developing in Japan (*dōshite susumanai ka*?).

One of the stories that probably received the greatest attention was that of Yuka and Sosuke. Various TV specials were dedicated to the child's fight against his rare disease, and to the brave attempt to save his life through the cutting-edge operation by Kimura-sensei. His case featured both in local and national news, as well as on a variety of TV shows, and even celebrities showed their support for the child. Perhaps because of the extraordinariness of both his disease and the intervention he underwent, Sosuke's experience was never closely associated with the debate on the reform of the AOT. Emphasis, instead, was put on the personal and tragic vicissitudes of the child and his mother, showing even more clearly the power of children's stories in arousing public interest.

As with the fund-raising, the idea of innocent children's wasted lives mobilised affective and moral responses, focusing attention on the problem through a sort of emphatic identification with the people affected by it (cf. Chapter 3). Through the media, young patients' families shared their experience of illness and, in this case, of grief. The public plight of *tokō ishoku* families thus became more than a simple illustration of the phenomenon of organ shortage; it effectively contributed to redefining what was, in Sato-san's words, a "minority issue" in terms of a new social problem.

Writing about public policy in Japan, Goodman (2002b) comments that social problems do not 'emerge' from given situations but are created when a group of individuals identify the existence of specific conditions and define them as undesirable: they are 'discovered' through experts' analyses and/or victims'

access to media, and measured into practical phenomena that calls forth practical solutions. In such a fashion, through the public plight of *tokō ishoku* families, the low organ donation rate of Japan became a problem of organ scarcity that was putting the lives of people at risk, especially those of its most vulnerable citizens. *Tokō ishoku* successfully bound the issue that the *ZōiRen* had long denounced in the form of a problem that affected society at large and required immediate solutions.

## Resolutions and Open-Ended Solutions: 'Japan, the Ambiguous'

With the petition, the Kumanos joined the activities of the *ZōiRen* and, with other patients' families, they became the public face of the transplant advocates. In the months leading up to the vote, as media coverage intensified, the stories of people (especially young children) maintained on life-support for several months in a condition of brain death began to appear on the news, reiterating the arguments on patients rights that upheld the debate in the 1990s (see Chapter 1). The issue of the determination of brain death in children became a problem of particular concern. Paediatric patients are resilient to brain injuries and have an increased capacity for recovery, the determination of brain death in children requires stricter criteria than in adults to take into account these physiological variances. What is more, since age is considered a determinant factor affecting the patient's survival capacity, children are said to be more likely to survive for long periods in a condition of so-called 'chronic brain death' (Shewmon 1998). Clinical protocols that take these factors into consideration were already in place in Japan, but the plan of a reform to abolish the age limit on organ donation raised anxieties concerning the possibilities that physicians could be entitled to withdraw life-support from young patients against their parents' will, and the harrowing stories of families caring for chronically brain dead children begun to appear on the media (Yamaguchi 2011).

Brain death was still at the forefront of sharp ideological oppositions in the Diet, as well as being the gateway to practical solutions for a reform. After the Konō Bill had set in motion the process of deliberation, opponents of brain death submitted various alternatives aimed at obstructing the reform advocated by the *ZōiRen* (see Appendix 2). Although not reflecting a radical opposition to brain death, the alternative to the Konō Bill remained nevertheless nothing more than a series of political compromises. Born from the work of bureaucrats tinkering with legal clauses, they aimed at presenting politically palatable solutions that addressed the problem of paediatric donation (arguably the most urgent issue at stake) while leaving untouched the sensitive issue of brain death. Without changing the definition of death, they also left substantially unaltered the general conditions of organ procurement; in particular the requirement for a donor card and the age limit on paediatric donations, which in most cases was lowered but not abolished. If approved, then, these policies were unlikely to produce any significant effects in terms of facilitating organ donation.

On the other hand, the Konō Bill met all of the transplant patients' requests: abolition of the donor card and introduction of an opt-out system, under which families' consent alone is sufficient to authorise donation, and abrogation of the age limit. The two amendments, however, rested on the premise that brain death is human death. Whether or not the patient was above the age for making a legal will or had ticked the right box on the will card ultimately wouldn't matter because once the diagnosis was confirmed, the person would be already dead and therefore had no rights to protect or exercise (Kuramochi 2012; Ida 2011).

> The most straightforward way (*ichiban sukkiri*) [to reform the law] would have been by defining brain death as human death. In fact, however, things got more complicated than that. […] Konō Tarō is very direct and outspoken, and once during a hearing session at the Diet, he put it very clearly (*hakkiri*) that brain death is human death and his bill was based on such premise. But the media soon picked up on that and argued that such a straightforward statement shouldn't be included in the law, because there are people who don't accept brain death as human death. Personally, I think the best way would have been to define brain death as death upon the law. But

> the thing is, even if you do so, in the end the choice of whether or not to donate is up to the individual. So, in the end, it didn't really matter. […] Of course, a uniform definition of brain death, which is the international standard, would have been the simplest way. That was the idea of the Konō Bill. But that comment raised such a debate. It was evident that a law that defined brain death as human death was impossible. It would have ruined our chances of having the reform discussed altogether. […] During the deliberation, we held a meeting to decide our strategy at the Committee for Health and Welfare Affairs. […] I argued that in my opinion the law should clearly state that brain death is human death. But the legal experts replied that the reform was, and had always been, about organ transplants, so we had to look at the next level, not discuss whether brain death is human death. The law, they said, didn't have the authority to deliberate so far (*soko made kimeru kengen wa nai*). Nakamichi-san was there too. And at that comment he kind of grumbled:
> "Oh, come on!"
> As if to say our chance was lost. But there was nothing else we could do (*shōganai*). It was impossible to go that far. And we still wanted to do something to reform this law. That's how the story went. That's the story behind the story (*urabanashi*).
>
> (Komeno-san)

In 2005, the Kon*ō* Bill was amended, introducing the right for patients' families to object the determination of decease following a diagnosis of brain death. The new bill, now renamed 'Bill A' to differentiate it from the alternatives submitted by the opposition, was intended as a compromise to intervene on the practical issues at stake (the out-out system and the age limit) without alienating the consensus of the moderates with a radical redefinition of brain death.

With the amendment to the Konō Bill, *ZōiRen* too was faced with the question of how far they could compromise on their requests. Nakamichi-san put it to a vote, and one of the groups in the league officially split from *ZōiRen* as they voted down the Bill A. For some, like Ashida-san, the redefinition of brain death was *the* essential condition for achieving an increase in organ donations. Organ donation, they thought, should be made available as an option for families to consider on the basis that the patient was dead; the alternative solution, that required the explicit consent of the grieving family in order to declare the patient dead, would always affect the smoothness of any donation process, even with the right bureaucratic conditions in place. Put simply, the death of the donor should be the premise for organ donation, not the

other way around. With the situation of other countries in mind, Ashida-san regarded the redefinition of death as a necessary and non-negotiable requirement for an efficient system of organ procurement.

The turn taken by the political debate on the reform forced transplant advocates into redefining their quests and focusing on the issue of *tokō ishoku* as a practical and politically appealing issue to mobilise the support they needed. With the beginning of 2009, the deliberation in the Diet entered the final stage and *ZōiRen* tightened up its lobbying activities. People described the months heading towards the vote as a period of cautious optimism and momentous anticipation. The schedule was tight (*giri giri*), and so was the margin of promised votes that *ZōiRen* had managed to put together. With the opposition submitting concurrent bills until the very day of the vote, the political trade-off around the reform risked eating away the *ZōiRen*'s support, and the different political majorities at the two Houses (*nejire kokkai*) made the situation even more precarious. Counting on the chart, Komeno-san and the others were confident they could make it through, but they knew they had no second chance. *ZōiRen* had to make sure the busy schedule of parliamentary work could accommodate the vote on the reform among the many issues still pending before the dissolution of the Diet for the general elections of August 2009. The prospect of having newly elected members in the two Houses risked nullifying the negotiations patiently carried out during the previous five years, and the political climate could well turn against *ZōiRen'*s plan if the LPD, traditionally their closest ally, were to lose its political majority, as eventually happened. Under the circumstances, if Bill A didn't get the majority of votes at both the Upper and Lower Houses, the discussion of a reform would have likely been shelved for another few years.

If possible, the political climate heightened people' expectations even more. The vote, on July 13th 2009 was a historical moment for transplant medicine in Japan as well as personally a very significant event for those who had worked for it, particularly for Nakamichi-san, who after the vote got appointed as head of the JOTNW, the first transplant patient to occupy the position and (he remarked) the first official that was not parachuted in the role from the high ranks of the MHLW. According to Nakamichi-san, the transplant

patients' lobby was an unprecedented case in Japan's recent history of patients directly shaping political decisions. While his reading might be not historically accurate, it nevertheless sheds an important light on how the *ZōiRen* managed to promote change as a minority group (Kingston 2004). As Norgren argues with regards to abortion policy in Japan, change is not automatically synonymous with a victory of society over the state, and liberal over conservative politics, for indeed what emerges from the case of transplant advocacy is that the capacity of *ZōiRen* to forge alliances and strategically pull strings with those in a position of power was decisive in having their claims recognised (2001). It is not without reason that Feldman (2000) talks of "ritual of rights", underlining the symbolic character of rights assertion that people make to promote their interest. In the case of transplant advocacy, both the strategy of the political lobbying and the undoubted impact of *tokō ishoku* families in mobilising public support and reaching for the ears of the media both contributed to influencing the political decision and precipitated the resolution of a question that had been pending for more than a decade.

If the case of transplant patients calls attention to dynamics of change, it also shows how this builds up slowly, and how it takes form through compromises more than sudden transformation. As Allinson (1990) indicates, this is particularly true in the case of Japanese politics, suggesting that behind the seeming stagnancy of official public policy decisions are in fact long-term processes of negotiation. The result of how politics are negotiated in Japan, is therefore that resolutions rarely accommodate entirely the requests of one party, and policy is often open to interpretation in the way they are drafted and enforced (*ibid.*).

> There were two issues at stake with that law: one was brain death as human death, and the other was transplantation as a problem that concerns human life. There is no straightforward relationship between the process in which the two have been sorted out and the final outcome. The result has been different than the initial goal. But it works. Maybe for Europeans it is different, it is more like a resolution that requires a clear 'yes' or 'no', but one thing that it is said to be peculiar of Japanese people is our ambiguity (*aimaisa*); that we can see the same thing in either one way or another. So you could argue that this law states that brain death is human death, but

> you can also take it in the opposite way. […] The *Nōshi Rinchō* set the process of policy-making in motion, but in the end it remains unclear what position it actually took. What did the *Nōshi Rinchō* say? I think that in there you can really read something about the Japanese.
>
> (Shimada-san)

As just seen, the passing of the reform was dependent on the compromise over the redefinition of death. In this way, while the reform erased the condition of organ donation from the legal definition of brain death, it also introduced the right for patients and their families to object to the legal determination of death on the basis of the neurological diagnosis. The position taken by the Japanese legislators was that the law had no authority to deliberate what constitutes the end of human life. In this respect, the current Japanese law remains identical to the former one in what is maybe its more interesting aspect and represents a rare case of public policy that allows the right to self-determination on death (Bagheri 2007; Lock 2002: 181).[71] Instead of giving a normative definition of brain death as either equal or different to human death, the Japanese law describes the condition in relation to legal concepts of the body (*shintai*) and the corpse (*shitai*), and in this way it maintains the possibility of considering it as both a terminal condition or death in the proper sense.

# Conclusion

Coming at the end of the ethnography of transplant recipients, this chapter illustrates how their life trajectories, so profoundly shaped by the problem of brain death in Japan, have come to interweave with the debate on the definition of death. While showing how Japanese recipients have successfully mobilised to assert their claims in the public arena, I have proposed looking at the process of legal regulation of brain death and transplantation as a site of identification and management of conflict. From this perspective, the experience of patients'

[71] For a discussion of the principle of self-determination in Japanese bioethics see Kato and Sleeboom Flaukner (2011b). For an overview of the legal implications of the definition of death in Western debate see Veatch (1977).

lobbying activity reveals how the controversy over the definition of death was neither a philosophical nor a scientific question but a profoundly political one. At stake in the legal debate over brain death, with which Japan has grappled for the last decades, was the negotiation of social anxieties over the medicalisation of death and the conflicting imperatives to save lives by means of transplantation technologies. Drawing on the concept of *ongaeshi* and on the experience of *tokō ihsoku* families, I have illustrated how these negotiations were a way to configure networks of mutual obligations within a community, in this case defined by its national boundaries. The ways in which the plight of Japanese children dying for a transplant became the issue that again raised public concern about the brain death problem, after years of unsuccessful attempts by both politicians and transplant rights advocates to reform the national law on organ donation, shows that what is shared in the process of regulation of this medical technology is not just body parts but life itself, in the sense that the parameters of what counts as a 'waste of life' and a 'good death' are negotiated against each other.

The ethnography provides refreshing insights into how policies on public health are negotiated in Japan, revealing important dynamics of social change while also complicating the interpretation of the negotiations and compromises these involve. From this perspective, I have shown how, despite the great emphasis on the reform, the current law still maintains an ambiguous definition of brain death. While Shimada-san rightly pointed out that in this regard the Japanese law is one on its own, the national policy on brain death and transplants raises questions of more general relevance. What role does the law play in the social fabrication of life and death? How much of the complexity and uncertainty of the debate on brain death can and should be taken into account by public policies (Younger et al. 1999: 115-161)? And what consequences do the answers to these questions produce in practice? The next chapter looks at these problems by exploring how the current Japanese policy is worked out in practice.

# Coda

Through our experience we've received a lot of support: during the fundraising campaign, and then from the medical staff, the doctors, and the interpreters in America. In this respect, our experience was really good. Then, when we came back we had this chance [of being involved in the lobby for the reform] through Endo-sensei, who had been working on this for years. Looking back now, the fact that Shuichi died was, of course, terrible. But among those who lost a child, I think we were lucky, because at least we could do something that helped us filling up the sadness for his loss (*kanashimi wo umeru*). When he died we couldn't donate his organs, but even so we had the chance to do something, and I like to think that what we did in a way contributed to make this first case [of paediatric donation] possible.

(Kumano Natsuko)

In that situation Bill A was the only chance, so I guess there was nothing else we could do (*shōganai*). But I regret it (*kuyanda*). That's not what we wanted.

(Ashida-san)

We sat up to do it, and we made it, even if we were just common people. It was not a grass-roots movement; it was just the five of us. But as five people we become a group, and we moved the Parliament (*kokkai ga ugoeta*). And you know what? It was really fun. We worked together with the MPs, and we had the support of the doctors [of the Transplant Association], but it was the five of us who started it in the first place. It was us who fought on the first line. And it was really fun!

(Shimada-san)

*SIX*

# Brain Death in Clinical Practice

The vote of the reform of the Act on Organ Transplants was regarded as a potential turning point in the long-enduring debate on brain death in Japan. Despite the political compromises described in the previous chapter, the reform clearly aimed at promoting efficiency in organ procurement. In this sense, while still maintaining the right of patients and their families to refuse the determination of death following the neurological diagnosis, the redefinition of brain death as no longer dependent on the patient's will to donate organs, unmistakably represented a major shift in the conceptualisation of death, and one that could have significant practical implications. According to Yamazaki (2013) the vote of the reform signalled a significant departure from the rationale underpinning the previous law. Compared to the debate that led to the vote on the law in 1997, he argues, on the occasion of the reform in 2009 the new discourse on organ shortage glossed over the ethical and scientific controversies that still remain open about the definition of death, shifting the attention away from the cure of the "brain dead person" (cf. Morioka 1989) and focusing instead the role that the determination of brain death plays in the broader political economy of organ procurement (Yamazaki 2013).

From this point of view, it was not only transplant recipients and advocates that regarded the passing of the reform as a historical moment. The media unanimously emphasised that "brain death is now human death" (*nōshi ha hito no shi*) (*Asahi Shinbun* 2009a, 2009b; *Yomiuri Shinbun* 2009c). From a less sensationalistic perspective, academics too promptly revived the debate on brain death and transplantation, interrogating the legal and conceptual

implications of the new definition of brain death (Kuramochi et al. 2012; Machino et al. 2009). The question in the immediate aftermath of the reform was whether, and how, the new law would have changed the long-enduring impasse on organ transplantation in Japan (Aita 2009; Bagheri 2009).

During my fieldwork, more than one year from the enforcement of the new policy, people usually expressed the confident belief that organ donation would become more common in Japan, but they were also clear that it would take time and gradual readjustments on the ground for this change to materialise. Data about organ donation in the aftermath of the reform showed that the removal of bureaucratic impediments to organ procurement had a considerable impact in increasing the number of donations. On the other hand, however, figures also indicate that most of the new cases of donations happened after cardiac arrest and that the rate of procurement from brain dead patients was so far only minimally altered, thus suggesting that clinical decisions about brain death still remain the crucial site of negotiation in the open dilemma of defining death.

This chapter interrogates how these decisions are made at the level of clinical practice. Referring back to previous anthropological research on the topic (Lock 2002; Namihira 1988), and drawing on the recent work of medical sociologist Aita (2011), whose pioneering research provides the first comprehensive analysis of end-of-life care in Japanese hospitals, I illustrate the findings from the interviews conducted with eight neurologists and neurosurgeons working in intensive care. The selection of the interlocutors isn't intended to be sociologically representative; on the contrary, the clinicians who participated in this part of the research express positions that can be considered relatively marginal because of their active involvement in the debate on end-of-life care in the ICU and/or organ donation. Drawing on their experience, I thus look at the determination of brain death (*nōshi hantei*) in clinical practice across the different moral and political economies of care and organ procurement.

# Changing Deathscapes[72] and the Medicalisation of Death in Japan

In Japan, as in other post-industrialised societies, an increasing number of people end their days in a medical context, whether in a hospital ICU, a hospice, or supported by at-home care. As 'the brain death problem' shows, in Japan the national debate on the medicalisation of death has been especially focused on the right for patients and their families to continue treatment, while the so-called 'right to die' has so far been considerably less relevant than in North America and Europe. While Japanese associations in support of assisted suicide and active euthanasia (*anrakushi*) have been engaged in the debate on the right to die for a long time (Long 2005), their claims for the rights of patients and their families to decide when to 'pull the plug' have never raised the sort of public attention that has accompanied highly visible cases in other countries (Aita 2012). Even in the case of brain death, as seen, the strongest arguments for the legalisation of the new death came from transplant advocates rather than proponents of the right to die. Accordingly, public policies have traditionally been oriented towards the protection of the 'right to life', meaning the possibility for terminal patients and their families to continue artificial life-support independent of medical judgment (Williams 1996; see also Feldman 2000)

The result is that in Japan, intensive medical intervention in the end-of-life, and artificial prolongation of death are especially common, even when therapeutically futile for the patients. Long illustrates that compared to North America, decisions about end-of-life in Japan are less conditioned by the financial constrains imposed by medical insurance coverage, and are deliberated through prolonged negotiations between families, patients and physicians (2005). Whereas in North America the prolongation of medically futile treatment is regarded as harmful to the patient's dignity, Long argues that in Japan greater importance is given to the involvement of the patient's significant others in the process of death (Long 2001, 2003). Instead of putting

[72] Part of the chapter was presented at the 2013 IUAES panel 'Disjunctions of deathscapes: ways of suffering, dying, and death', from which I borrowed the concept of the deathscpape.

emphasis on principles of individual autonomy and dignity, the very idea of the patient's self is negotiated case by case between physicians and the family, and end-of-life decisions are adjusted accordingly (*ibid*.). Lock similarly argues that in the late 1990s the principle of patient's autonomy was regarded as a relatively recent introduction to the discourse on the ethics of clinical practice and was largely a family decision (Lock 2002). The medical futility of treatment was not a matter of concern; instead, physicians' attitude and declared intentions tended to emphasise their commitment to prolonging life, and families were able to sustain hope for longer (*ibid.*).

Recent investigations into end-of-life decisions show that Japanese physicians still express a particularly conservative attitude towards the withdrawal/withholding of life-prolonging treatment, so that even when care is unquestionably futile it is seldom interrupted (Aita 2006, 2011). The practice, however, calls attention to the problem of the allocation of scarce resources, especially in a country like Japan, with an especially numerous population of the elderly, dying of chronic diseases (Aita 2012, cf. Long 2005). Furthermore, it raises serious ethical questions concerning the rights of patients and families who object to the futile prolongation of treatment (*idib.*).

Against this background, the so-called problem of 'death with dignity' (*songenshi*)[73] seems to have increasingly become a matter of social concern in Japan (Aita 2011), and public polls show that the majority of the population opposes the prolongation of intensive life-support treatment in terminal cases. In 2012 a parliamentary commission was formed to draft a law authorising the interruption of life-support treatment for terminal patients, and in 2010 the Japanese Association of Acute Medicine (JAAM) issued its first official directives on end-of-life care to compensate for a gap in practical guidance that had so far made the withdrawal of life-support effectively impracticable.

Clinical negotiation is also a question of increasing relevance to organ donation. The recent change in policy to allow organ donation under family consent alone has made the role of clinicians all the more crucial. Under the new system, any patient diagnosed as brain dead is now legally a potential

[73] Different from *anrakushi*, assisted suicide and euthanasia, *songaeshi* refers to the withdrawal/withholding of medically futile treatment (see also Long 2005).

organ donor, and the active cooperation of intensive care clinicians alone is that which can materialise the effects of the policy. In fact, efficiency in organ procurement is for the best part determined in the clinical setting, and the cooperation of intensive care physicians is crucial. The identification of potential donors, by means of a prompt diagnosis of brain death, and the productive management of the request to the next of kin, are the two most important phases in the donation process and in practice are largely taken care of by attending physicians in the ICU (Uryūhara 2012). Uryūhara shows that Japan ranks at the very bottom of international statistics in this respect, with approximately 8% of potential donations actually completed, compared with an average of 50% in Spain, 48% in Belgium, and 33% in Switzerland (2012: 139). It is estimated that around 2,000 patients become brain dead every year in Japanese hospitals; of these the JOTNW receives notification of roughly 100 cases (Aruga 2010), and the number of actual brain dead donation is usually no higher than sixty.[74]

In fact, physicians often lament that the task of cooperating with organ procurement overlaps with their routine work of clinical care and can become an extra burden for the already overstretched medical staff (Aruga 2006). One of the hospitals I visited was then trying to implement a transplant-support unit, with dedicated in-house coordinators who could step in and take care of the donation process. A further strategy to facilitate organ procurement was the introduction of new reimbursement schemes to relieve the donor's hospital of the financial burden that comes with allocating internal resources to the management of the donation process. The crucial node, however, remains how to reconcile the need of procuring organs with the dilemmas surrounding the end-of-life, in the medical setting.

[74] Data from the JOTNW.

# The Heart Matters: the Diagnosis of Brain Death in Clinical Practice

When I asked him to describe how he deals with brain death in clinical work, Yasuda-sensei immediately specified:

> Brain death is the end point. First, we work to rescue the patient so that he/she doesn't become brain dead.
>
> (Yasuda-seseni)

In practice, brain death is the end point of a process of care, which has its own logic (Mol 2008). Talking of brain death in clinical practice, physicians frequently underlined "the psychological burden" (*seishintekina futan*), or as one of them put it, "the problem of the heart" (*kokoro no mondai*). By this, they refer to the emotional strain of dealing with a condition that leaves no room for hope. While usually discussed in terms of a psychological burden, "the problem of the heart" is in fact deeply embedded in the practical tasks physicians are called upon to take care of.

The first is disclosing the diagnosis to the family, and informing them that there is nothing left to do. Having 'the talk' with the family requires disclosing information in a way so that the family can fully understand that the prognosis is irreversible and terminal, without being left with second thoughts, doubts or even worse suspicions. Communicating the diagnosis also means that from that moment on, clinicians have to carry on their duties in a profoundly changed situation, one they are not trained for. The diagnosis of brain death doesn't lead automatically to the interruption of treatment; in fact, it is functional to give the family time to accept (*ukeireru*) the loss. The role of physicians, therefore, changes from one oriented towards the provision of medical treatment, to one that needs to accommodate for grief care[75].

[75] In practice, it is nurses who are closer to the family and take care of much of the work of assisting the bereaved, but 'the talk' is the responsibility of the attending physician, and it is the physician who is in charge of negotiating the various treatment options with the family (see more below on this point).

> A first thing to say is that we're really surrounded by death. In the hospital, people die everyday […] It's not that brain death brings about different feelings, but for sure you know [the family] have feelings that you cannot understand, a sadness that you cannot imagine. That's the first thing: you have to deal with it knowing that you cannot know.
>
> (Shibuya-sensei)

Anthropologist Namihira (1988) famously wrote that behind the resistance towards brain death is physicians' discomfort in dealing with terminal diagnoses. Terminal diagnoses, Namihira illustrates, force intensive care physicians to abdicate their role to save lives; they cast doubts on clinicians' personal drive, the moral obligations they owe to patients and their families, and the meanings they attach to and derive from their work (*ibid.*). Underpinning their professional attitude is the very character of their specialisation, for intensive care is all about saving lives in critical conditions, and often by means of desperate and heroic solutions. From this stance, brain death is the ultimate defeat.

> Most emergency care physicians don't want to deal with brain death. Brain death is almost the end of life; emergency care physicians save lives, we save patients and save their families. Brain death is giving up (*akirameru*).
>
> (Kubota-sensei)

> When you disclose [a diagnosis of brain death] to the family, you're saying that you're giving up. Even if [you?] continue treatment there's really nothing more you can do [to help the patient], so you have to ask them to give up. That's very difficult to explain. It's like a drastic switch from a stance where you're trying to provide the best treatment possible to just giving up. Maybe emergency care doctors and neurosurgeons are more used to [dealing with sudden traumas], while for neurologists and paediatricians it could be even harder. It's like if until the morning you've done your best, and from the evening you don't try any more. That's difficult to explain to the family.
>
> (Abe-sensei)

> You take care of the patient day in day out. You do the tests, you see some values get better while others get worse. You discuss the patient's condition with the family, you explain what improved and what didn't, and since these are particularly severe cases, they are followed closely and things get discussed every day in detail. And then after you've been with the family every day and you've tried

> hard for the patient to recover, you get to the point where there's nothing more to do. And that is… is hard to explain to them if you think of their feelings.
>
> (Morinaga-sensei)

As these extracts highlight, the clinical care of brain death is profoundly tangled up with the moral obligations of care, as well as with the routines, goals, and organisation of clinical work in the ICU. In practice, brain death can manifest through different clinical scenarios. In some cases, the person might be initially aware and/or responsive to treatment, only for his/her condition to deteriorate over time. In other situations, when the patient is admitted urgently to the ICU, the chances are that he/she might be already brain dead when put on life-support, although this is obviously impossible to tell with bare eyes. Whatever the scenario, brain death is always the result of a failed attempt at rescuing a patient. It is not a condition diagnosed 'on the scene' or immediately upon arrival at the hospital. Indeed, as Yasuda-sensei pointed out, what physicians do to handle brain death, is try to avoid it. Brain death materialises at the juncture when clinical practice has to shift from curative treatment to terminal care.

This shift from treatment to end-of-life care is particularly severe in intensive and emergency medicine. On the one hand, this relatively young medical specialty has witnessed in the last decades an unequalled decrease in mortality rates, due to recent developments in resuscitation technologies and trauma medicine, challenging received knowledge about the limits of the irreversibility of death. On the other hand, end-of-life care is no longer confined to the hospice and palliative care for chronic diseases; more and more often, it is in the ICU that decisions are taken on when to stop resuscitation, when to pull the plug, or when to withhold treatment. Physicians thus emphasise that end-of-life care in the ICU (*kyūmei shūchū shūmatsuki no iryō*) has its own particular problems which are different to palliative care. Terminal conditions in the ICU, in fact, frequently result from unexpected and highly traumatic events, such accidents, and suddenly face families with delicate decisions that in the case of chronic diseases would be deliberate and processed over time.

As Kaufman describes in her compelling ethnography of end-of-life care in American ICUs, the coexistence of heroic treatment and terminal care means that the shift from curative to palliative medicine in the ICU is often rapid and fraught with problems (2006).

> Other than in relation to certain diseases (e.g., terminal cancer or end-stage AIDS) death is rarely spoken of or foreseen until shortly before it occurs. Medical care emphasizes the stabilization and normalization of organ systems and the gathering of laboratory data in service of that stabilization. Especially in the ICU, concrete life-sustaining activities preclude the anticipation of death. Clinical medicine in the ICU is like surgery - its gaze falls only on a carefully circumscribed field, the analyzable interior of the body. A wanting life is rendered invisible, or nearly so, in the reading and the treating of signs of the body's pathology. Disease is treated until there is no more physiological response to therapy. Only then is death expected. Only then does it "need" to be acknowledged by hospital staff.
>
> (Kaufman 2006: 29)

For these reasons, the aspect of clinical work where the emotional burden of dealing with brain death appears most problematically is not the provision of treatment but the diagnosis of the condition. Like the majority of the forms of life that one can find in ICUs, brain death is not a sudden event, nor a self-manifest condition. It is therefore in the practice of formulating a diagnosis that, in Kaufman's terms, death becomes something that needs to be acknowledged.

Acknowledging death is different than just expecting it. The lack of vital signs, the unresponsiveness to treatment, the state of deep coma are all indicators of probable brain death that physicians normally observe as they take care of the patient and monitor changes in his/her condition. It is on the basis of these clinical observations that the formal diagnosis is then conducted, so that in fact brain death must be anticipated in order to be diagnosed. The difference is that while expecting death allows people to just wait for it to happen, acknowledging that the process is already in motion entails the responsibility of taking action over it.

Clinically speaking, brain death is an ethically 'simple' case, one that in fact spares much of the ethical dilemmas of more uncertain conditions routinely treated in ICUs. The certainty of the prognosis and the complete lack of

consciousness and responsiveness of the patient means that nothing can affect the patient's chances of recovery or even his/her quality of 'life'. On the other hand, however, the diagnosis and handling of brain death has enormous practical implications for organ donation.

## The Hearts Matter: Brain Death and Organ Donation

If the co-operation of intensive care physicians is key to the success of the enterprise of organ donation, in practice, clinical work and the task of organ procurement are often described as conflicting. Dr. Kano, one of the clinicians anonymised in other passages of this chapter, writes in a professional journal about transplantation that:

> For patient's families, emergency medicine and transplantation medicine are not tied to each other, neither [do] they want them to be so. For the family of the patient who arrives in A&E, emergency medicine is about life (*sei ni mukatte*); transplantation medicine about death (*shi ni mukau*)
>
> (Kano 2008: 35)

Coupled with the problem of dealing with a terminal prognosis, the utilitarian function of the diagnosis of brain death puts the moral obligations of care under further strain.

> I know there are many children waiting for a new heart. I even took part in public events about organ donation. I know how important transplantation medicine is. But I also know very well the feelings of the family on the 'donor side' (*donaa saido*). [I know] their sorrow. So I think there's a limit to what we can do to cooperate proactively and try to increase the number of organ donations. I think our priority is taking care of their feelings (*kokoro no keea*).
>
> (Yasuda-sensei)

> I'm a neurosurgeon and an intensive care physician; in other words, I'm on the 'donor side'. In this position, I have absolutely no interest in pushing for the promotion of organ transplantation. Still, if a patient of mine has the wish to become a donor and unfortunately becomes brain dead, then I'll do what I can to fulfil his/her will. I

> don't join initiatives to promote organ donation, but I do cooperate if my patient is in the situation. I think that's the stance of most clinicians. I fell quite uncomfortable (*iwakan*) about intensive care physicians actively engaging in the promotion of organ donation. That's weird. I first want to take care of my patients.
>
> (Ueda-sensei)

> Up to the moment when the patient becomes brain dead, all the treatment is for that patient. Once the person is brain dead, however, in some cases, she will become an organ donor, and that's ultimately to help other patients. So as an IC clinician who is working for that patient, you're confronted with two issues. First, from that moment on [your work] is about saving another patient you've never even seen. And second, there's the fact that you haven't been able to save your patient who's there in front of you. For IC physicians, using the body of the patient we tried to save in order to help some other patient is... well, it's difficult. It requires a kind of emotional switch (*kimochi wo kaeru*). You'll hear that doctors [don't diagnose brain death] because they're busy, but that is nonsense: we're always busy. If [diagnosing brain death] was to help our patients, we'd do it, even though we're busy. When people say they cannot do it because they're busy, they're actually saying they don't want to do it because that's not for their patient's benefit. Obviously when you're busy you cut on extra-work, but the point is this is extra-work because it's not aimed at helping your patient. So in a way, the two issues I told you actually boil down to the same thing. No matter if you're busy or not, you just don't see it as part of your job, because it's not to help your patient. Logically, and ethically, it can be argued that it is the responsibility of IC physicians [to cooperate with organ donation], but in your heart you can't think of it as your job.
>
> (Abe-sensei)

As Abe-sensei's comment illustrates, in case of donation, clinical care is reconfigured from the care of the patient to the task of procuring organs. Transplant coordinators step in, and the provision of treatment too is readjusted in the function of the single organs. As Hogle describes, conflicting interests can be at stake between what is best for the overall condition of the body and what is more effective to maintain the functions of the internal organs because tissues in different organs can deteriorate at different paces and require different care, and this in turn can affect physiological processes in various bodily systems (Hogle 1999).

Hogle writes that this process of so-called “donor-management” is the new frontier of organ preservation, as it targets single organs while they are still inside the donor’s body (Hogle 1995, 1999). Donor-management gives rise to ambiguous situations in which therapies normally provided to living patients (both mechanical life-support and drug therapies) are deployed to maintain a body that is now “reimagined as a container and life support system for the targeted organs” (1999: 147), while at the same time treatment that would never be used on less injured patients is used to maximise the condition and quantity of organs procured (1999: 149-151). On the other hand, to some intensive care physicians, the very idea of ‘donor management’ seems inappropriate altogether, as “it refers to the management of the organs (*zōki wo kanri suru*) instead of the care of the person (*hito wo miru*)” (Kano 2011: 453).

From this perspective, clinicians emphasise the importance of carefully managing the interaction with the family, and whether to confute or support the point, they all expressed the concern that requesting the family to consider organ donation could cast doubt on the physician’s commitment to provide treatment in the best interest of the patient and undermine the relationship with the next of kin. As is often pointed out, clinicians in Japan have been traditionally reluctant to broach the issue of organ donation with the next of kin, considering it disrespectful and hurtful to approach the bereaved family with such a request (Lock 2002). In this regard, clinicians’ uncooperative, when not openly opposed, attitude towards organ donation is often indicated as the main reason behind the local low rate of organ procurement (see also Uryūhara 2012).

On the other hand, all the medical professionals interviewed emphasised that, at least in principle, the possibility of donating organs should be offered to families as one of the various options of care that are available for terminal patients, as expressed though the paradigm of so-called ‘*opushon teiji*’ (giving an option). Despite their different stance on organ transplantation (some were definitively more in favour than others), clinicians emphasised that discussing organ donation with the family isn’t just aimed at obtaining consent, but is also a way to fulfil the will of patients and families who desire to donate. Comparing the local practice with the approach in U.S.A., one physician stressed that in

Japan organ donation is not linked to the goal of increasing the efficiency of organ procurement but is part of end-of-life care, and the role of the coordinator is not to talk the next of kin into donating but is to provide grief care. This approach encourages clinicians to assume an active stance on organ donation as part of their ethical responsibilities towards terminal patients and their families, and was regarded as particularly important in light of the recent reform on organ donation, which makes it possible for the next of kin to decide on donation even when the patient doesn't hold a donor card.

Two of the clinicians interviewed, Abe-sensei and Morinaga-sensei, worked in hospitals that were implementing a protocol for 'option giving'. Introduced after the recent reform of the law on transplant. The protocol aimed at providing information on end-of-life care and organ donation to all the families of patients who met the criteria of brain death. In discussing how they managed the protocol, both Morinaga-sensei and Abe-sensei stressed that the role of the attending physician ended when disclosing information to the family, and that while clinicians had the responsibility of providing support and arranging a talk with a transplant coordinator, if the family wished it, discussing organ donation was not their role. When the JOTWN coordinators take over, physicians should step aside. Obviously, the hospital staff would still be in charge of the medical aspect of the work, but it would now be up to the transplant coordinator to conduct the consultation with the family, negotiating for example whether to donate after cardiac arrest or brain death and obtaining written consent to the pronouncement of death for transplant purposes. Keeping a neat separation between the clinical aspect of organ donation and the practical management of it was regarded in this case as a way to reconcile the moral obligations of care with the task of organ procurement.

Kitanaka-sensei was of a different school of thought. As attending physician he felt the responsibility of being in charge throughout. He had his own way of dealing with 'his' patients and their families, one that involved managing both the medical treatment of the first and the psychological care of the second. He was all but willing to leave the reins of his ICU to transplant coordinators, and he was in fact quite picky about the personnel that the JOTNW sent over. The scepticism was mutual. Some transplant surgeons and

coordinators regarded Kitanaka-sensei's stewardship, and his attitude of supervising every aspect of the process of donation, as paternalistic, unpractical and unnecessarily time-consuming. In his own view, Kitanaka-sensei's method was worthy of praise, for leading to a high rate of consent to donation, as well as good medical care. After all, he thought he knew about treatment better than the coordinators, who intervene halfway through the process.

Whether by stepping back or by taking charge of the process of donation, physicians tried to reconcile their moral obligations towards the patient and the family with the utilitarian use of the body as a source of therapeutic goods. In this regard, while cooperation with organ donation still appears to be a problematic node in clinical work, the paradigm of '*opushon teiji*' provides an important framework to subsume organ donation into the wider discourse on end-of-life care.

## *Mitori no Iryō*

Kitanaka-sensei stands on a stool by the door of one of the ICU ready to take a picture. "Wait, did I take it?" says Kitanaka-sensei half seriously, still standing on the chair. Inside the room, people chuckle. The scene is from the TV documentary "Medicine for life and death"[76], on the work of Kitanaka-sensei and his team. Inside the room, family and friends pose around the hospital bed where a young man lies attached to life-support machines. The young man was hospitalised a few days earlier. Kitanaka-sensei is shown during a private meeting with the family while he explains to the middle-aged parents that their son is brain dead. The day after the group picture, the entire family is again at the man's bedside. In the operating theatre (OT) down the corridor, the transplant team is getting ready to procure the kidneys after the patient is disconnected from life support. The family has been waiting in the room for a while, as Kitanaka-sensei is going back and forth to the OT. When the moment comes, everyone stands. At the end of the bed a woman holds the man's ankle

[76] Sapporo TV, first broadcasted in 2010.

sobbing. Kitanaka-sensei stands next to the respirator. On the other side of the bed, children and women rub the man's arm and leg underneath the sheets. The old mother caresses his head with fast movements, turning her head back and forth from her son to the monitors displaying his vital signs. Kitanaka-sensei speaks a few words. The scene goes on. Nothing happens. People are heard sobbing. The physician bows his head and thanks everyone once more. He gives a few more words of condolence and praises the family and the patient for having *gambatta*[77] so hard. Everybody seems to be waiting to know when to leave.

Because brain death is not equated with human death in Japan, the question of whether and how to withdraw life-support treatment is left to the kin and the attending physician to negotiate. In theory, four options are available: 1) continue treatment without change; 2) continue artificial ventilation while changing other treatment (most commonly, by gradually decreasing the dose of drugs to stabilise blood pressure); 3) withdraw treatment altogether; 4) donate organs. In practice, the complete withdrawal of life-support (3) is almost never practiced, and organ donation (4) is scarcely given as an option.

Aita (2011) indicates that once initiated, artificial ventilation is rarely discontinued. Even when medically futile, artificial ventilation is regarded as a form of basic care rather than advanced/extreme treatment because switching off the ventilator would result in the immediate death of the person and is therefore conceived as equivalent to causing rather than allowing death to happen (*ibid.*). The path usually preferred is therefore to continue ventilation, and possibly regulate drug therapy. The gradual withholding/withdrawal of drugs, Kitanaka-sensei explained, can be discussed with the family when the patient's condition seems to require particularly intensive care, for this indicates that the organism's capacity to sustain itself is weakening and physicians can anticipate that, if continued, heavy doses of pharmaceuticals might have detrimental effects on the body appearance. In this way, the patient is kept off artificial ventilation allowing cardiac arrest to 'naturally' happen through what is also defined as a 'soft landing approach' (Aita 2011).

[77] See the discussion on *gambaru* in Chapter 2.

The whole process can take up to several days, weeks, or even months if the patient is stable and the family desires to continue treatment. During this time, families can rely on full insurance coverage for the costly expenses of a bed in ICU. Decisions, it appears, are thus gradually deliberated over the course of events, even though the medical futility of treatment is certain from the start. In practice, most of the time families are given only some of the options clinically available. But in the process they are given time.

Physicians stressed how time is an essential part of care. Even with the most severe cases, physicians waited at least one day before making the diagnosis and disclosing the prognosis to the family. They bide their time before deciding what to do, gauging several factors other than clinical symptoms and the schedule of organ procurement. They observe the family's reaction and responses in consultation with nurses, who are the closest to the patient's relatives. Clinicians waited before talking about organ donation or treatment withdrawal, if they ever did. They mentioned options only to leave them for later discussion. They judged each case in its own regard on the basis of the family's (presumed) preparedness to make, or just even consider, certain decisions. None of the interviewees expressed the concern, often mentioned in the bioethical literature, that this waiting could be agonising for the family. Time, instead, was regarded as productive.

Rather than being given the news that the patient is dying, the family would gradually become accustomed to the idea that there is nothing left to do, figuring out the course of events through repeated exchanges with the medical staff and by participating in the decisions made in the clinical setting. In fact, these negotiations don't translate necessarily into a wider range of choices, but they nevertheless provide an outlet for patients' families to respond to the rapid shift from curative to palliative treatment that characterises clinical practice in the ICU. In this way, physicians stressed, families can fully accept (*ukeireru*) the imminent death of a loved one. In practice, it seems, leaving a margin of ambiguity is more important than coming up with clear-cut definitions; not knowing can practically be a more useful strategy (see Lock 2002; Long 2005; cf. Murray 1981), especially when it comes to a diagnosis so publicly debated and medically hard to grasp as 'brain death' (see more below).

In clinical practice, the way people try to make the most of this ambiguity goes by the term *mitori no iryō* (literally, treatment for the care of the dying). *Mitory no iryō* is the way people commonly talk of "end-of-life care", and differently to the technical jargon "*shūmatsuki no iryō*", it refers not just to treatment options but also to the creation of a supportive environment for terminal patients and their families. This extends past the point of death. Kitanaka-sensei's hospital for example offered a service called 'angel make-up' (*enzeru meekappu*) to prepare the body for viewing. Washing, preparing and applying make-up to the body was particularly important for patients who suffered trauma or were treated for prolonged periods with drugs that can cause swelling and damage the appearance of the patient. It was also of the greatest importance for organ donors.

Organ donation was a sensitive part of *mitori no iryō*. Kitanaka-sensei not only supervised the pre-operative care, many times he also joined the transplant team in the OT during the explant. Nurses took care to add some flower decorations to the chilling boxes containing the organs, and offered the families to write cards to send with them. The medical staff supervised the dispatch of the organs, in the same way as they would attend the discharge of the body of dead patients. Care, Kitanaka-sensei explained, doesn't terminate at the point at which clinicians run out of therapeutic possibilities, but extends until the patient and the family leave the hospital, in whatever ways that happens. Organs were no exceptions, because "in the end, they're not just things (*yappari mono janai*)".

Strathern argues that at stake in the detachment of body parts, is the relationship between the body as a person and the body as a thing (2004). What is reproduced through the cultural construct of body "parts" is in fact the "wholeness" of the body as a person who cannot be reified: thought of as "part", Strathern writes, organs can be made into things, but never "whole" things on their own (*ibid.*). A similar logic seems to orient the care of the body's appearance and handling in functioning to reinstate personhood at the moment –the end of life– when this is both most precarious and important. At the very juncture where treatment could reduce the body to an object-like status,

medical care becomes a resource to "accompany a person in the process of death", as Kitanaka-sensei describes.

"But whole bodies", Strathern also notes, "are, in another sense, part-persons […] for as well as being singular, persons can also be plural", at least in Malaysia (2004). Similarly to what Strathern writes about Malaysia, personhood in Japan is not defined in relation to an intimate self, and emphasis is put instead on the social relationships the person is part of, particularly the inner circle of family members (Kondo 1990). As discussed in Chapter 1, this notion of the self was at the base of arguments advanced by patients' rights advocates and legal scholars against the redefinition of death as human death, for this would have meant stripping death away from the networks of social relationship that makes a person, and gives the physicians alone the authority to deliberate over it. Physicians drew upon these ideas to stress that: "in Japan informed consent is the consent of the family"[78], and Shibuya-sensei even argued that it is not just abstract interests we are talking about; the very body of the person is shared with his/her closest one, for the person is conceived as part of the life of the family (*kazoku no seimei no ichibu*). Aita (2011) thus argues that because the brain dead patient is both unconscious and terminal, clinical care is oriented towards the bereaved family rather than the person, although the practice of continuing intensive treatment raises ethical doubts about the respect of the person's best interest. In this way, the right to self determination recognised by the law is not quite equivalent to a system of living will, and appears instead to be oriented to providing grief care for the family, thus reinforcing the primacy traditionally assigned to collective decision-making and to the role of the family in clinical choices (cf. Tsuji 2011).

Kitanaka-sensei's hospital was one of those that were working on implementing *mitori no iryō* in practice. Families of dying patients were encouraged to spend the remaining time with the person; they were provided with a private space by moving the patient into a single ICU, and offered the possibility of negotiating flexible visiting times. Some found it unbearable to be exposed to the view of a loved one in such a condition, but others used the chance quite creatively. Kitanaka-sensei had a vast gallery of pictures and

[78] Abe-sensei, personal communication.

videos of brain dead patients and families, which he often used in his presentations at conferences. They show relatives as they help out the nurses; a mother washing the hair of a patient; a friend giving him a haircut; another one taking care of the manicure. One person got an extra bed in the ICU to sleep with the patient. Most commonly, people bring personal objects: a picture of a car if the person had a passion for motors, toys for young children, a book to read some passages from, even pets. One man was dressed up in his baseball uniform. Another was taken out in his bed for "a walk" in the ambulance drop-off area. A young couple is shown with their two-year old baby. The body of the child rests inert on the father's lap, as the parents talk to the camera for a video together. The pictures and videos show people posing, and although relaxed, they also appear somewhat staged. But they are supposed to be, in a way.

Like the contemporary funerals Suzuki describes (2000), *mitori no iryō* seems to centre on the positive commemoration of the person and the beautification of the body, rather than on rituals of separation from the spirits or the purification from the pollution associated with the death. The practices in the ICU are celebratory and commemorative experiences, and are part of what *mitori no iryō* is for: to build good memories, share sad moments, and begin to grieve. The mixture of clinical care and rituals of death, on the other hand, is not new. Lock describes for example that clinical practitioners in Japan practice *kuyō*, a ritual to appease the suffering of the dead, for the spirits of the bodies dissected (2002). In this way, the living continue to accompany the dead in the journey to the after-life, albeit through different practices, that reflect different conceptions of the dead (or here comatose) body as a medium of the individual's presence rather than a source of impurity (Suzuki 2000). In *mitori no iryō*, the person is treated as alive, beautified and positively commemorated, and indeed it seems that more than appeasing the dead spirits, the care of the body serves to appease the bereaved.

The body is the means of negotiation and enactment of these practices. It is the medium and the agent of personhood for and though others; whose life, artificially sustained, allows the time for care. It can also be a site of conflict.

> The prolongation of treatment in a condition of brain death looks like harming the patient. It could be painful. It could be that he, or she, didn't want it. I feel very strongly about that. In fact, according to a large survey on end-of-life care here in Japan, 80% of people reportedly replied that, had they been terminally ill, they wouldn't want to prolong treatment […] Even if the person cannot experience pain, it's still doing something to a person that he or she doesn't want. If the person was conscious, he/she wouldn't want it, so I think it's unfair to continue treatment without knowing the person's will. I'm not saying that shouldn't be possible, but that it should be done in accordance with the person's will. To me it's exactly the same as fulfilling the person's will to donate organs, it's a form of respect to the person's will (*ishi wo sonkei suru*).
>
> (Ueda-sensei)

Ueda-sensei's comment draws attention to how the 'logic of care' is never fully coherent, and in practice is often fraught with conflicts and contradictions. On the one hand, his argument highlights how the increased public attention on the issue of end-of-life care seems to articulate a stronger ideal of individual rights and autonomy, so that the person's own interest and that of the family can be perceived as conflicting (cf. Aita 2011). Further, Ueda-sensei's point underlines how the privileged attention to providing grief care to the family by allowing them time to be with the patient can also constrain people's choice, making it virtually impossible to accommodate the will of those, both patients and next of kin, who object to the prolongation of futile life-support treatment. From this perspective, it appears that structural constraints significantly determine what choices are made available to people (cf. Kaufman 2006). Further, physicians act as the ultimate gatekeepers of families' decisions, judging case by case on the basis of the family's perceived preparedness to discuss various options of care, they in fact decide to whether, when, and to whom, these options are presented.

While presenting internal conflicts, the practice that Japanese physicians describe also offers insights that are relevant to the context. Ethnographic literature gives compelling evidence of how the brain dead body is a source of ambiguity everywhere, not just in Japan. Describing clinical practice in North America, for example, Lock reports how physicians and nurses care for brain dead patients as if the person still "lingers in the body" (2002). Hogle too indicates that physicians in the U.S.A. and Germany recognise the brain dead

body as a corpse only after organ procurement (1999)[79]. The same is true for patients' families. The emphasis on the right to die in the Western debate shouldn't lead to the conclusion that the withdrawal of treatment is a response in and of itself (Kaufman 2006). Writing about England, Kitzinger and Kitzinger, for example, show that families of severely head injured patients, including brain dead patients, negotiate between different notions of death, both as a biological event and as a relational process (2014). As they navigate this phase of "in-between" and reconcile the loss of a loved one, families express clearly that the person is still present, "at least as a subject for 'being with' and saying goodbye to" (Kitzinger and Kitzinger 2014: 246). An Italian nurse similarly told me that in his experience the practice of 'forcing the ICU open' (against hospital regulations) for family members to view the person help the bereaved to come to terms with death, while also having a positive effect on consent to organ donation.

In Japan, the national controversy on brain death provided clinicians with a rich range of social, professional and cultural resources that explicitly draw attention to various dimensions of the problem of care of terminal patients that go beyond the medical definition of brain death. The legal ambiguity over the definition of brain death and the possibility of relying on medical insurance for the costs of life-support treatment appear to be significant factors in allowing the space for people to negotiate delicate decisions about the end-of-life with a wider margin of flexibility. Whether these possibilities actually translate into forms of care that are able to better accommodate people's feelings remains an open question, as Ueda-sensei's comment suggests. From an anthropological point of view, however, the Japanese case offers important insights into the ethics of end-of-life. As the mention of ethnographic cases in contexts other than Japan indicates, however construed, brain dead bodies are brain death persons everywhere (Morioka 1989, 2001), and any failure to conceptualise this is a loss of important intellectual resources in the way we frame the bioethical discourse on the category of brain death (cf. Strathern 2004). In this sense, the Japanese experience is not just indicative of a particular social construction of

[79] See also Younger et al. 1989.

the person; it is also a more sophisticated social analysis of the problem of brain death in clinical practice.

## (Mis)Diagnosis: Clinical and Legal Brain Death

So far I have illustrated how conflicting goals and even the shifting ontologies of the body are at stake in the diagnosis of brain death (cf. Mol 2002). The ways in which people negotiate these factors depend on the questions of what needs be diagnosed and for what purpose.

Because of the emotional strain associated with brain death, Japanese medical practitioners have traditionally been reluctant to make such diagnoses. In practice, many reportedly regard it an unnecessary burden to go through to the standard protocol for the determination of brain death given that the diagnosis would not lead to any therapeutic options for the patient and would only result in a dreadful conversation with the family (Namihira 1988; Aita 2011). Most commonly, clinicians rely on partial/non-standardised diagnostic procedures to evaluate the patient's condition and decide when to stop curative treatment. While putting emphasis on showing their commitment to prolonging life and doing everything possible to save life, physicians would often take charge of decreasing the administration of oxygen in order to allow death to occur "naturally" while still leaving space for "miracles" to happen (Lock 2002: 271). In this way, however, families are often kept in the dark about the patient's situation and informed only when death has already happened, or are given only partial information to suggest that death is approaching without however being actively involved in the deliberation of end-of-life decisions.

The problem is not limited only to brain death, but has emerged as one of the most critical issues of medical practice in Japan (Feldman 1985). Until recently, it was widespread practice among Japanese physicians to avoid disclosing terminal diagnoses like cancer, brain death or other conditions treated in the ICU. Facing terminal patients and their families with the dreadful prognosis of imminent death was deemed as "unethical", considering the public

perception that surrounds certain conditions (Long 1982). Because brain death is clearly associated in the public discourse with organ donation and the withdrawal of care, physicians would commonly avoid disclosing the diagnosis to families in order not compromise the relationship of trust with the next of kin by suggesting their intention to interrupt care or even take advantage of the patient's imminent death to procure organs (Namihira 1988; Aita 2011).

The definition of brain death as human death to allow organ donation played into this moral economy of end-of-life care. With the legalisation on organ donation from brain dead patients, in 1997, the Japanese criteria of brain death, as defined in the so-called Takeuchi code (*Takeuchi kijun*), were taken as a new legal definition of death. The Takeuchi code, approved in 1984, lays down the diagnostic procedure to determine brain death in clinical practice and prescribes the repetition, over an interval of at least six hours, of the following examinations:

1. Evaluation of the preconditions;
2. Ruling out of confounding factors;
3. The determination of coma deepness;
4. Electroencephalography
5. Examination of fixed, dilated pupils;
6. Brain-stem reflexes, including the apnoea test

The policy on organ donation, the aim of which was to provide practical guidance for organ procurement, indicated that when the tests were first completed and gave a positive result, physicians would initiate the process of consultation with the family on the grounds that the patient now clinically qualified as a potential donor. Once consent was obtained for organs to be retrieved, then, the end of the second repetition of the tests would be recorded as the official time of the decease.

During the debate on the law, however, opponents of brain death, including intensive care physicians, objected that, as it was, the policy theoretically enabled the lawful withdrawal of life-support without the family's consent, for it equated the diagnostic procedure with the legal determination of

death, and at the same time demanded that the diagnosis was made *before* consulting the family. As a way out of this catch 22 situation, the last test in the Takeuchi code, the apnoea test, was removed from the mandatory tests for the first examination.

The apnoea test (*mukokyū tesuto*) is the part of the test to verify the absence of brain-stem reflexes. These are clinical examinations that can be carried out at the bedside, that consist of simple manipulation of the body; they provide external stimuli, like exercising pressure on the eye-lid or projecting light into the eye, that would be sensed by a functioning brain stem and elicit automatic responses. The apnoea test verifies the absence of the impulse to breathe, which is regulated by centres located in the part of the brain stem (the *medulla oblongata*) that has the longest survival time. It is, therefore, the kernel of the diagnosis of brain death. To test the absence of respiratory drive in a patient on artificial ventilation, however, requires the temporary removal of life-support. This produces an increase in the level of carbon dioxide, monitored through blood tests, that should generate the stimulus to breath detectable by the movement of the chest. Since it involves switching off artificial life support, the test was not prescribed at the level of the first clinical examination.

This allows the diagnosis of "possible brain death" (*nōshi to sareuru jōtai*) that was sound enough for physicians to consult the family and contact a transplant coordinator, but also ambiguous enough to leave undecided whether the patient actually met the legal criteria of death and should be removed from artificial life-support. This difference was formalised in the policy by formally distinguishing between so-called 'clinical' (*rinshōteki nōshi*) and 'legal' (*hōteki nōshi*) brain death.

That the determination of brain death is divided in two phases in not peculiar to Japan and is determined by the fact that the condition develops over time and therefore requires a period of observation to verify the persistence of symptoms and conclude that the process of death of brain tissues is indeed completed and irreversible. In this sense, the two phases in the determination of brain death are regarded as merely descriptive of the chronological unfolding of the diagnostic procedure through the repetition of two sets of tests, and the whole process is theoretically conflated into the final time of death (cf. Lynn and

Cranford 1999) . Distinguishing between 'clinical' (*rinshōteki nōshi*) and 'legal' (*hōteki nōshi*) brain death, instead, the Japanese policy shifts the focus from the underlying condition that the diagnosis reveals to the practical functions that this diagnosis fulfils as a means to assess the patient's condition and/or to determine death in order to enable organ procurement.

In this way, however, the Japanese policy created a situation of potential confusion (*konran*) in practice (Kano 2008; Aita 2011). First, it suggested that the complete determination of brain death, including the apnoea test, was of relevance only to organ donation, and that in other cases the determination of brain death could be left incomplete. Secondarily, it implied that (brain) death could be either clinical or legal and that the two could be different from each other; an arguably a disturbing prospect given the widespread public concern over this medical category.

With the reform of the policy in 2009, therefore, the distinction between clinical and legal brain death was amended, and the two were renamed respectively diagnosis (*nōshi shindan*) and determination (*nōshi hantei*) of brain death. In fact, since the revised law doesn't give a uniform definition of death (see Chapter 5), the policy still maintains that the diagnosis (*shindan*) doesn't require the apnoea test, and that the final determination (*hantei*) is subject to the family's consent and is the only one that holds legal value to withdraw treatment and pronounce the decease. Despite this elements of consistency with the previous policy, the formal amending was intended to receive the comments, advanced by medical professionals, that beyond the bureaucratic procedure concerning organ donation, the diagnosis of brain death is primarily a medical matter and that from such a point of view there is no 'clinical' or 'legal' brain death but only 'brain death in the proper sense' (*hontō no imi nōshi*). 'Brain death in the proper sense' is a phrase clinicians often use to refer to the condition as it is determined by adhering to the standard diagnostic protocol. Anything less, they agree, doesn't count as a proper diagnosis of brain death from a medical point of view.

This emphasis on the correctness of the diagnosis must be understood in light of the debate on end-of-life care and the importance of 'giving an option' (*opushon teiji*). The consequence of physicians' reluctance to disclose terminal

diagnoses was that, in fact, patients and their families were disenfranchised from exercising their rights concerning end-of-life decisions (Feldman 1985; Long 1982, cf. 2005; Aita 2011). The clinicians interviewed were therefore particularly critical of this long-established tendency. They all pointed out how it was unethical and contrary to the moral obligations of care for the patients and the family. At the same time, in the way they discussed the issue, they also pointed out that disclosing information to the family is not necessarily considered to be functional to take active decisions with regard to treatment withdrawal and in most cases disclosing the diagnosis serves instead to give time and space to the next of kin to be with the patients and take part in *mitori no iryō.* Giving options, albeit in fact these are often limited, is therefore a way to counter the tendency not to disclose information to families, representing a shift in the ethics of clinical practice towards a more active involvement of the family in the decisions about end-of-life, but also a more active role on the side of the physicians in overcoming the psychological burden of the terminal diagnoses and taking care of the process of dying.

The clinicians interviewed thus expressed very clearly the stance that in the face of the concerns over the medicalisation of death, their commitment cannot be limited to saving and prolonging life at any costs and that the role of medical professionals is increasingly that of taking care of the process of dying, whether by negotiating the interruption of clinically futile treatment or giving the family time to participate in *mitori no iryō* or even by offering organ donation as a way to fulfil patient's last will at the end-of-life.

In this economy of care, the role of the diagnosis is particularly important to start the process of negotiations on these end-of-life options, and the clinicians interviewed all stressed that a sound diagnosis of the patient's condition is an important tool in clinical practice, even when it has no role in relation to curative treatment. From this perspective, Abe-sensei stated that at his hospital, and in many others in the country he said, physicians always made the full diagnosis of brain death, including the apnoea test. When I asked him how they would accommodate the family's decision not to carry out the final determination (*hantei*) and keep the person on artificial ventilation, he explained that:

> Even if we were asked not to do a diagnosis (*shindan*), our job as clinicians is to verify with precision (*kichitto miru*) the patient's condition. Even if we were required not to proceed with the determination of brain death (*nōshi hantei*), there is a medical reality (*igakutekina jijijtsu*), and we check that medical reality. You can use the Japanese protocol for the determination of brain death (*nōshi hantei*), or the Harvard protocol, or the Danish one, each country has its own, with roughly the same tests. Our job is to perform a medical diagnosis. To not perform the 'determination' of brain death (*nōshi hantei*) simply means not to use those criteria.
>
> (Abe-sensei)

In his analysis, the determination of brain death as a matter of practice (the act of determining the patient's condition) is conflated with the determination of brain death as a standardised diagnostic procedure, and through it, with the biological condition that this is designed to test, what he calls the "medical truth". It is this that the diagnosis attests and that, in turn, defines the clinical options available.

> The legal determination prescribes we do the tests twice over a six hours interval. At the level of the first examination we do the determination of brain death (*nōshi hantei*) according to the approved procedure. Then we do the second examination, because that's the rule. That's the rule to determine brain death legally. In a way that's etiquette (*sahō*); it's for performance (*manaa*). It's earlier on that you understand you have to give up on treating the patient, and that's what you've got to communicate to the family: the fact you have to let it go. Then you can also propose to donate organs, and that's what the legal determination is for. But before the legal determination, you've already done the diagnosis […] and if you use [the protocol] then you can already know that what you diagnosed is brain death.
>
> (Abe-sensei)

While all the clinicians interviewed agreed with Abe-sensei on the relevance of the diagnosis to inform the patient's family, the way they discussed their work in practice suggests a very different scenario.

## (Mis)Diagnosis I: “We Don’t Use the Word ‘Brain Death’”

Morinaga-sensei was head physician at the critical care department of a hospital in central Tokyo. At the time when I interviewed him, they were implementing a new protocol for the ‘option giving’. This was designed in the aftermath of the reform of the policy on organ donation and was in use in various centres, including Abe-sensei’s hospital. The protocol provided pragmatic guidance on how to discuss terminal prognoses with families of severely head-injured patients, in order to relieve the medical staff of the burden of evaluating each case on an individual basis, while also offering complete information to all families.

Physicians noted down the results of the clinical examinations on a form that was then handed over to the family. On the back page, the form presented a space to fill in with a one-line explanation of the patient’s clinical record, followed by a pre-printed description of the prognosis that anticipated the patient’s imminent and inevitable death.

The front part of the form instead consisted of a checklist of clinical tests for the attending physician to go through. These described exactly the symptoms assessed with the official brain death determination (*noshi hantei*): deep coma, dilated pupils and absence of brainstem reflexes including the lack of respiratory drive.

*From the interview with Morinaga-sensei:*

> Me: Could you explain me how you go about informing the family that the person is in a condition of brain death?
>
> Morinaga-sensei: You cannot say the person is in a condition of brain death.
>
> Me: Why?
>
> M: You can’t say it until you have done the brain death determination (*noshi hantei*).
>
> Me: I see. [What] I noticed in fact is that in here [in the pre-printed description of the prognosis] brain death is never

mentioned, but judging from the tests I guess you use this procedure on patients who are likely to be brain dead, right? So how do you discuss the patient's condition with the family?

M: Families might have a different view of brain death than medical professionals, for example they often confuse it with PSV, so we don't use these categories. Instead we usually explain that, for example, 'the person has lost brain functions (*nō no kinō ha ushinawareta*)' or that 'there's nothing left to do (*chiryō shitemo modoranai*)'. As you see there's a space to fill in here [to summarise the diagnostic findings]. Here we write things that the family can easily understand, like I just told you. If it seems they might not understand we'd put it for example as: 'the person won't wake up (*me ga samasanai jōtai*)'. In a scientifically correct way you would say 'possible brain death' (*nōshi no kanōsei ga aru*), but it just makes no sense to use the word 'brain death'. There's no reason to do so. The only case when the word 'brain death' is important is after you've finished the [legal] determination.

Me: Does it ever happen though that relatives themselves ask whether the patient is brain dead?

M: Yes it does in fact.

Me: And what would do then?

M: The thing is, brain death is not brain death unless you do the brain death determination (*nōshi hantei*). So we explain it in the ways I told you […] We talk of 'brain death' only after having concluded the legal determination, but we go through that only when they wish to donate organs. In other cases we don't do it.

Me: You don't?

M: No, absolutely not. Because the [apnoea] test is dangerous.

[…]

Me: But doesn't this [the check of absence of respiratory drive] refer to the apnoea test?

M: No. In the apnoea test you take blood samples and measure the level of carbon dioxide objectively (*kyakkantekini*) with the ventilator off. We don't switch it off, and we observe, we kind of get a sense (*kanshouku*) of whether the person is dependent on it. It doesn't make up to evidence.

## (Mis)Diagnosis II: “He’s Been Brain Dead for One Year”

Kitanaka-sensei met me in the main hospital hall and walked me down a narrow corridor to the critical care department. The department was a very different space than the crowded hall we’d just left behind, and rather unlike other hospital wards too.

Adjacent to the ambulance drop off area, at the front of the hospital, and separated by a shutter, was the emergency room arrival, an unfurnished space fitted only with technical equipment that looked like all the bits in a garage. Kitanaka-sensei walked to one of the pieces of equipment, a sort of metal box sitting on a trolley, and picked up a catheter to show me how he would attach the person to the machine upon arrival.

Attached to this room was the main CCU, the largest room in the department. It was a wide space, with a dozen beds approximately, overlooked from a distance by the physicians’ desk. The dim light of the early-autumn morning filtered in from large curtained windows. The room was bare. Cards, newspapers, children’s toys and the objects that visitors normally bring to hospitalised patients do not fit in the CCU. It wasn’t bleak, however; just strangely empty, with the medical equipment barely noticeable on the walls. There were no patients buried under thick tangles of tubes, no rush to treat new emergencies, just doctors doing some routine work at their desks. A young man laid in a bed, the sheets rumbled in one corner as his legs stretched out in a twisted position. Kitanaka-sensei explained he was admitted recently after a car accident, and was now stable enough to be transferred to another facility. The man had his head bent on one shoulder, and his closed eyes were moving. He had no chances of improving, said Kitanaka-sensei as we stood at his bedside. I assumed he must have been unconscious.

Detached from the main CCU, Kitanaka-sensei showed me the private IC rooms. A man in his forties occupied the first one. He laid seemingly asleep attached to the respirator, as the rhythmic noise of the machine somehow made the movement of his chest more visible beneath the sheets. His feet looked swollen, the skin thin and stretched. He had been moved there a couple of weeks earlier after being diagnosed brain dead and Kitanaka-sensei thought

that he didn't have much time left. The man in the next room was brain dead too. Kitanaka-sensei told me he had no children, but his wife came regularly to visit him. He looked frail and skinny, but overall it looked like the prolonged treatment hadn't taken too hard a toll on his body. Kitanaka-sensei said he repeatedly consulted with the wife about gradually withholding drugs, but she had declined to take action as long as the situation was somehow stable. "He's been here for more than one year now", said Kitanaka-sensei.

*Form the interview with Abe-sensei:*

Abe-sensei: One year is too long. I think that's not really brain death. I think it's a mistake. But if you don't do the test, then nobody can tell. If the physician waited one year without doing a diagnosis because the family didn't want to [pronounce the death] then it's misconduct. […] There are such stories because they're kind of odd and curious. Nobody talks of the thousands of patients who die normally after a brain death diagnosis, but if one survives longer than a while it becomes a story. But anyway I think that was a misdiagnosis in the first place. You said there was no apnoea test, right?

Me: Yes.

A: And maybe they didn't even take the brain waves.

Me: No, they did. They did all the exams [in the protocol] but the apnoea test.

*From the interviews with Kitanaka-sensei:*

Kitanaka-sensei: According to the case, I'd do imagining tests, like MRI or CT scan, and check the blood flow. The absence of cerebral blood flow is a reliable indicator [of brain death]. These tests don't cause any harm to the patient [unlike to the apnoea test]. But they cannot be done at bedside, you've got to move the patient. International protocols, including the Japanese one, are devised to be carried out at bedside, but the truth is that there are tests that give you a clearer picture, only they're more laborious and not all facilities have the right equipment, so they're not taken as standard tests. The current protocol only comprises of clinical examinations, that is, tests that can be done at bedside. The apnoea test is one such test, but it's dangerous. So I'd rather use a test that requires me to move the patient but doesn't aggravate his/her condition, and that gives clear results too. There are such methods, they're just not

> standardised. That's how the procedure was devised, and it's unlikely that it'll change because it's accepted internationally: no protocol includes these [ancillary] tests, so they're deemed unnecessary. But personally I don't think they are. I mean, if you want a greater degree of clarity, these tests can rule out any mistake. So you see, it's not easy at all.

## The Medical and the Clinical

> In pathology the first word historically speaking and the last word logically speaking comes back to clinical practice. Clinical practice is not and will never be a science even when it uses means whose effectiveness is increasingly guaranteed scientifically […] One does not scientifically dictate norms to life. But life is this polarised activity of debate with the environment […] The physician has sided with life. Science serves him in fulfilling his duties arising from that choice.
>
> (Canguilhem 1991: 226)

While everyone agrees that the apnoea test is absolutely necessary to have a diagnosis of brain death, in practice, physicians don't usually carry out this examination unless required to determine the death of the patient for the purposes of procuring organs (Aita 2011: 121). As the case of Morinaga-sensei illustrates, the formal apnoea test is not necessary to determine that the prognosis is terminal and inform the family of the imminent death. The apnoea test serves in fact to establish that the patient meets the formal criteria of brain death in order to donate organs, because brain death is the only terminal condition under which organ procurement from heart-beating patients is allowed under the law. Because the preferred patterns of care involve keeping the person on artificial ventilation until cardiac arrest, in the majority of cases the test becomes in fact irrelevant when not even confounding. Morinaga-sensei's comment about families who enquire whether the patient is brain dead suggests in this respect that maintaining a margin of ambiguity on the diagnosis allows people to focus on the strategies of care rather than on the underlying condition. Having a clear result of brain death, on the other hand, would force people to confront it, even if that was only to decide on the continuation of treatment *despite* the patient's condition.

Physicians gave a number of practical reasons to explain why they don't use the apnoea test, citing that it's more laborious than other examinations, that it exposes the medical staff to the risk of legal consequences of withdrawing life support, and that it's dangerous (*abunai*). In fact, if performed according to the accepted procedure, the test is considered to be safe for the patient (Wijdicks 2011). Nevertheless, it works by producing precisely the body reactions that treatment is intended to avoid. In this sense, the fact that the increase of carbon dioxide in the blood can be monitored within a safety threshold is irrelevant. The effects of the test are still regarded to be against the patient's interest, and the result is not related to any curative options.

Even when physicians use the test to determine the patient's condition for clinical reasons other than organ donation, they did so in order to strategise the patterns of care in dialogue with the family. Ueda-sensei, for example, said he performs the test in the majority of cases in order to be able to offer the family the possibility to withdraw artificial ventilation. In this case, the apnoea test was necessary to exclude a different result at the moment of the second examination which could force the family to overturn the decision taken, causing significant emotional distress.

Kitanaka-sensei, on the other hand, said that to use the test when the results of the other examinations were unclear and the diagnosis uncertain, appeared to constitute an obstacle for the family to accept the prognosis and deliberating a decision. In this case, the apnoea test was used in the same way as the other 'ancillary tests' Kitanaka-sensei describes, such as the brain imagining and the blood flow test. Some of these so-called 'ancillary tests' are considered as sensitive as the standard ones: in fact, they are even more precise and can produce "confounding results" as they capture residual brain activity in clusters of cells or neurons that are not considered to contradict the accepted definition of brain death. For these reasons, while clinically relevant to understanding the patient's condition (Sato 2003), the ancillary tests are not included in the official protocols for the diagnosis of brain death, which instead are designed to be easily performed in a standardised way, and aim at verifying the patient meets the defined criteria for the determination of death.

> From the point of view of medical science, once [the person is] brain dead, on the withdrawal of ventilation the heart will stop immediately so that's essentially death. But clinical medicine doesn't necessarily base its judgment on a scientific mandate. That's the case with all types of treatment. Put the case you know drug B is more effective than drug A. That's not enough to say you'll always use B over A in any patient. If as a physician you think that drug A works better on a patient's body (*karada ni au*), you don't have to use drug B at any costs if you think it can be not god for your patient, even if data say it's the best one. Even if that's the best from a scientific point of view, as a physician you always gauge what treatment is best for the patient through clinical interaction (*rinshotekina taiou*). That might not appear fully logical, but I don't feel it is (*kanjinai*). That's what "clinical" means. You've got to care thoroughly for the patient. There is a thing such a science, then there is the patient, and the doctor, and you manage the relationship among the three through the choices you make on the ground. Prioritising science…well you do somehow, but it's not about science at all.
>
> (Ueda-sensei)

In clinical practice, the usefulness of the diagnostic tests was not evaluated in light of their reliability to produce a diagnosis of 'brain death in the proper sense' (*hontō no imi noshi*). Ambiguity in the diagnosis is not always synonymous with a lack of reliable information about the patient's condition, and people appear to have various diagnostic possibilities: they can leave out some tests and make a diagnosis of 'possible brain death' (*nōshi to sareuru jotai*), or they can corroborate the clinical examinations by means of the apnoea test or the ancillary tests. Whatever the scenario, they gauge their possibilities in view of how the diagnostic tests enable or contradict certain patterns of care.

While medical diagnoses are usually considered to be functional, to determine the underlying condition in order to decide care, in this case the logic of care doesn't follow from but instead inform the diagnostic process. It is through this process, in turn, that bodies become (brain) dead or (terminally) alive. From this perspective, the process of determining brain death in clinical practice appears to happen in ways much messier than described by Abe-sensei, but in a way it is indeed a "permformative" practice.

# Conclusion

Despite the emphasis on the recent reform of the legal definition of death in relation to organ donation, the analysis of the diagnosis and care of brain death in practice indicates that clinical work has remained substantially unaffected. The ways in which end-of-life decisions are negotiated on he ground seem to depart only marginally from the situation during the years of the brain death problem (Long 2005; Lock 2002). In this respect, three important elements of continuity emerge. First, the role of the family is still predominant over the principle of individual autonomy. As the case of *mitori no iryō* shows the provision of medical treatment is not evaluated in light of the benefits and burdens for the individual patient, but appears to be oriented towards providing grief care for the family, by allowing them time to gradually process the loss and deliberate when and how to let the person die. Further, because the very notion of treatment utility/futility appears to be valued in relation to these patterns of care more than on a strictly medical basis, the tendency to prolong life-support treatment well past the point when the patient's condition is known to be irreversible continue to be largely common (Aita 2009, 2011). Finally, decisions appear to be negotiated by privileging diagnostic ambiguity over clarity[80], as this allows a wider margin of flexibility for people to deliberate decisions according to the situation on the ground (cf. Long 2005).

While these patterns of care remain predominant, they also offer space for change and renegotiation. In this sense, the experiences of the physicians who contributed to this part of the research reveal the particular attention given to issues that have traditionally remained marginal in the discussion over the ethics of clinical practice in Japan, such as organ donation, the disclosure of terminal diagnoses and the withdrawal of futile life-support. Physicians thus construed organ donation as a form of respecting the patient's and the family's last wills at the end of life, and emphasised the importance of disclosing information to the family in providing them time to be with the patient while treatment is continued. In this way, the experiences of the physicians

[80] See for example how Lock describes how she was reminded that physicians don't use the word 'brain death' (2002: 270), much as in Morinaga-sensei's case.

interviewed offer important insights into how medical professionals negotiate the need to reorient the ethics of their work, from the exclusive commitment to save life to the need to take care of the process of death, within the local moral economy of end-of-life care, informed by the focus on collective decisions and the strategic use of diagnostic ambiguity.

In light of how it is put to work in practice, the Japanese policy on brain death appears to be a case on its own. While the uniform redefinition of death as brain death presupposes that the medical diagnosis is taken as the condition to authorise organ donation on the grounds that the brain dead patient is dead to all intents and purposes, in Japan the reverse is true: the determination of brain death (*nōshi hantei*) is carried out almost exclusively when consent to organ donation has already been given, and the pronouncement of the death of the person is still a matter of family's choice. In this sense, Aita argues that the ambiguity over brain death that the policy maintains is praised by clinical practitioners because it allows them to reconcile the medical logic that underpins the diagnosis with the feelings of the people involved in the practice of care, including the family and physicians (2012). From an anthropological point of view, the case of Japan shows how the there is no logic outside the logic of care, and that medicine, even in its most scientifically sophisticated forms, such as modern intensive care, is always a therapeutic practice.

From this perspective, the experience of the determination of brain death in Japan contributes a valuable practical critique to the debate on this much-contested medical category. As discussed at the beginning of this thesis, the logical consistency in the formulation of concepts, standards and clinical tests of brain death remains a question open to dispute, and the practical function of this medical category at the intersections between the ethics of organ procurement and actual clinical work appears in many respects contradictory (see Chapter 1). While these controversies have prompted a heated discussion among neurosurgeons and bioethicists in North America and Europe, the debate has remained almost exclusively speculative, leaving out of sight the most important issue at stake: the fact that medical categories are always a matter of practice, and therefore have to be considered in light of the practical purposes that they serve and of the actual outcomes that they bring about

(Belkin 2014). The Japanese take on brain death and the experience of how this category is negotiated in practice offers a critique that is more true-to-life (or in this case, to death), thus providing precious intellectual resources to the bioethical debate on death and organ donation. On the other hand, as it follows from the ethnography of transplant recipients, the analysis of brain death in practice also problematises the practical implications of this sensibility towards death, casting its consequences far beyond the clinical setting within the broader economies of transplants.

# Conclusions

Along with caring for terminal patients and their families, a central part of Kitanaka-sensei's job is to seek new solutions to critical cases, pushing further at the limits of what can be done to bring back to life those who are on the brink of death. With this aim, he has been working for the past few years on a cutting-edge resuscitation technique involving percutaneous cardiopulmonary support (PCPS). PCPS is an artificial heart-lung machine consisting of an external structure, roughly the size of a computer, connected to two catheters that are inserted into the patient's major blood vessels. Through the first catheter, blood is drained out of the body and into the artificial lung where it is re-oxygenated before being pumped back into the patient's circulatory system via the second tube. Originally developed for use in heart surgery to sustain circulation in the absence of cardiac activity, PCPS has been recently put to test in emergency and trauma care to provide cardiopulmonary resuscitation (CPR). The device is used to rescue patients who have suffered sudden cardiac arrest, stabilising their condition by sustaining blood flow to vital organs, and in particular to the brain. Compared to manual stimulation of circulation or other more basic reanimation techniques, PCPS provides a more efficient replacement of natural cardiac activity and can be continued as a treatment for days or even weeks,. It has been shown to greatly improve the chances of recovery in cases that were once considered irreversible. Its potential benefits are in fact so promising that PSPC actually looks like a resuscitation technology in a quite literal sense, one that can bring people "back from the dead." And indeed the experience of one of the patients Kitanaka-sensei recently treated could easily be described in those terms.

A few months before my meeting with Kitanaka-sensei, during the frigid winter of northern Japan, a woman fell unconscious near her home. She was found the morning after, under a thick blanket of snow. When she arrived at the hospital she had no heartbeat and her body temperature was 13.5 degrees Celsius. From that, the doctors thought that she must have been lying unconscious in the snow for several hours –it takes seven to eight hours for body temperature to drop to 17 degrees– and dated the time her heart had stopped beating back to the night before. Treatment was promptly started, the body of the woman was warmed up and she was immediately put on PCPS to reactivate the circulation. One month later, Kitanaka-sensei told me, she left the hospital "on her own legs".

While recovering from a eight-hour long cardiac arrest is exceptional, and was indeed made possible only by the patient fortuitously being hypothermic, PCPS routinely allows medics to treat people who have shown no natural cardiac activity for as long as days. Put to rest as the machine takes over, the heart can return to its normal function even after prolonged periods of inactivity, a potential that was completely ignored and thus never actualised through basic CPR techniques and under clinical protocols that equate death with either cardiac arrest or brain death. The result is that patients who no longer than a few years ago would have been declared dead upon arrival at the hospital can actually make a full recovery.[81]

In this way, PCPS shakes even the seemingly safe definition of death as the apparent absence of signs of life in the body. "That's no miracle, that's common sense," says Dr Kano, knowing that his words are all the more powerful in the face of stories like those above. The implementation of PCPS in emergency care rests on the counterintuitive assumption that even when the heart is not moving, the person, or better said, parts of the person, are still functioning, and if they are kept healthy and alive by means CPR, the process of death can actually be reversed.

[81] According to the documentary '*Medicine for Life and Death*' (2010) data from 2007 indicate 26.6% survival rate and 21.5% conscious recovery rate compared to the national average of 10.2% and 6.1% respectively.

> When a patient arrives at the hospital in cardiac arrest you'd [normally] check to see if the pupils are fixed, and if there's respiratory and cardiac activity. Those are the three signs of death. Still, even when the patient is in such a condition, they might not be brain dead yet. So in a way they're not dead. [For this reason] it's unthinkable to diagnose the person [dead] as soon as they are brought to the hospital and go ahead with [organ] donation, as happens in America [using the protocol for NHBD]. My thought [in such a circumstance] is that there's a brain there that can be rescued. I know it, because I actually have experienced it.
>
> (Kitanaka-sensei)

If brain death meant displacing and reducing the process of dying from the body as a whole to the brain, PCPS confronts us with the dis-assemblage of death and therefore of personhood. Accordingly, the challenge with the clinical use of PCPS is not to simply resuscitate (parts) of the body, but to produce the possibility of a meaningful recovery for the person.

Crucial, in this regard, is time. According to Kitanaka-sensei, forty minutes is the longest that can be allowed from the moment the heart stops to when PCPS is started. After that, even though basic cardiopulmonary support has been provided throughout, the chances are that PCPS might turn out to do more harm than good, resulting in the patient being reanimated only to have suffered major and irreparable brain damage. Complicating clinical decisions about the use of PCPS in emergency care is the fact that the heart and the brain do not die at the same pace and in the same way. Kitanaka-sensei showed me his clinical findings represented in a graph that compares percentages of recovery in relation to the time of intervention for both the brain and the heart, respectively shown in blue and red. The image on the screen shows the two lines intersecting like an open scissor: with the horizontal axis of the graph indicating time, the two lines both decline towards the right as the figure indicating the minutes gets higher, but while the red line has a mild inclination, the blue one drops rapidly. The recovery of cardiac functions, Kitanaka-sensei explains to me, is correlated with but not directly proportional to time, also depending on the original defect that caused the cardiac arrest in the first place. When it comes to the brain, the odds of a full recovery are inversely proportional to time: the longer it takes to get the patient on PCPS, the worse the damage suffered by the tissues left without oxygen. As the figure for time

increases on Kitanaka-sensei's graph, the blue line drastically falls until it reaches the point where the chances are that even if attached to the machine the patient might already be brain dead.

CPR raises deep ethical dilemmas about withholding potentially life saving technologies from critical patients. While it can effectively restores cardiac and circulatory activity and thus brings back biological life to the body, CPR can do nothing to treat the body. In emergency and trauma care, the most daunting problem is the risk that in the prolonged absence of circulation the brain will suffer irreversible damage. This means that, if not administrated promptly and efficiently CPR risks resuscitating the person only to have them permanently impaired, the reason why many sign do-not-resuscitate orders. On the other hand, however, PCPS also involves another, equally dreadful prospect brought into being by the possibility, until recently unexplored, of artificially sustaining cardiac function for as long as days, during which the condition of the patient is constantly monitored. The problem arises when tests reveal that medical intervention has been rapid enough to prevent neurological damage, but time proves ineffective in restoring cardiac activity. Put it simply, in such cases the body is healthy and the person fully capable of consciousness, but the heart is not functioning. The only possibility of recovery would then be to substitute the failing organ, which ultimately means receiving a transplant.

That was the epilogue of the complicated but fortunate story of Saya.[82] Saya was brought to Kitanaka-sensei's hospital after she had suffered sudden cardiac arrest during a PE class at her junior high school. After days on PCPS and still showing no sign of spontaneous cardiac activity, the girl was transferred to a nearby centre equipped with a ventricular assistant device (VAD). VADs, or as they are normally referred to, artificial hearts, are portable devices much smaller than PCPS, which can be worn for a longer time and are designed to act as a bridge from a patient's terminal cardiac failure to the transplant. Once she received one, Saya got listed for a transplant in Japan, and at the same time her family contacted JASOT to start the fundraising that successfully brought her to the U.S.A. Saya's case was a lucky as much as it

[82] Saya's story is told in the documentary 'Nonfix' (2011) that Dr Kitanaka sent me a few months ahead of our meetings.

was a rare one. It is a story that shows what is possible, and yet most of the time unfeasible.

In fact, clinical, technical as well as financial factors[83] shape the use of PCPS in emergency care in such a way that when the patient does not regain normal cardiac function in two weeks, the only possibility is weaning them from life-sustaining treatment. Saya's youth and good health heavily influenced the clinical decision that saw her referred to another hospital for further treatment, a choice that would have made no sense if the patient had been older or debilitated by a long disease. Her family was spared the burden of taking into consideration the financial costs of PCPS, as her treatment was paid for by the school's insurance. The possibility of a transplant overseas, especially given her young age, might also have played a part in her family's decision to go ahead with treatment, making her eligible for the artificial heart. Artificial hearts have limited availability, and are a temporary support, so that in order to receive such a treatment the patient must also be a good candidate for the next therapy, a transplant, which in turn is rare in Japan. The decisions in cases like Saya's are therefore complex ones and involve both a clinical assessment of the patient's chances of surviving; the willingness of the family to undertake extreme measures in the face of uncertain outcomes; as well as the finances to pay for treatments, such as the transplant overseas or PCPS itself, that are not included in standard insurance schemes. That all these factors could play their part in clinical success is not impossible, but in many cases all it takes is one thing to go awry for the whole to fall apart. In fact, in a great number of cases, the weaning treatment is the only choice because, as Kitanaka-sensei puts it, "there's no next step." What makes these decisions particularly difficult, although they are not common, is the fact that the patient, even though sedated, has normal or close to normal cerebral activity and is thus fully capable of consciousness.

[83] For an analysis of PCPS withdrawal and withholding in ICU see Aita (2011: 75).

*From my field-notes*

Kitanaka-sensei: In such cases, we have to interrupt the treatment at that stage, even if the person is conscious. Of course you don't switch off the machine while the person is awake. We provide medication to sedate the patient.

Me: When you say conscious, what do you mean? What level of consciousness?

K.: [Potentially] they're fully (*jūbun*) conscious.

M: You're talking of people who could reason like you and me?

I remain silent but make a strange face at this point because Kitanaka kind of screams: "I know, I know!"

K: […] That's a recent problem. A problem we have since we've got machines for cardiopulmonary resuscitation […] It's terrible (*zankoku*). But that's our limit, at the moment. […]

M: What about the opposite case, when the heart comes back but in the meantime the patient has suffered major brain damage? Will the person have to live the rest of their life with some form of disability?

K: Those cases are relatively common […] If you don't reduce the time before the patient is put on PCPS then you cannot rescue the brain. Currently, even here at our centre, the average time to get the patient to the hospital is thirty-five minutes. That's probably even longer in Tokyo. According to my data, if you don't manage to get the person on the machine in forty minutes there's nothing you can do for the brain. In any case, sooner is always the better as you see [from the graph]. So you have to be fast. [On average] it takes thirty-five minutes for the patient just to arrive, so you're then left with five minutes to attach the machine. That's a strict working time. We can do it in four minutes, but…

M: Would you say four minutes is fast?

K: It is. We have very good results at this centre. But in other hospitals, like in Tokyo and even abroad, it can take much longer […] But if you don't do it fast, then there' really no point in doing it at all. We haven't started yet, but from next year we're planning on trying to bring the device itself to the scene, so we can attach it quickly to the patient. As I said, you have to be fast. You can practise doing it pretty swiftly at the hospital, and we've actually mastered it quite well. But even so, you have [structural] limits, so we're trying to work them out. It's the opposite of this.

He shows me an article on a protocol under discussion in the U.S.A. to allow kidney retrieval at the scene from patients who suffer sudden cardiac arrest and carry a 'do not resuscitate' order.

K: Our medicine is about rescuing the patient; this is to rescue the organs. What I want to do is to rescue the brain in order to rescue the patient. If we can make this bulky machine compact enough to be transported to the scene, we'll increase the number of people whose brain can be rescued (*nō wo tasukeru hito ga fuerareru*) even more. The problem is, you can rescue the brain if you're fast enough, but among those people whose brain you rescued there'll be some whose heart doesn't come back. Those too will increase. Well, I don't know to what extent but…

M: But it might increase (*kamoshirenai*)…

K: That's my dilemma.

*End of field-notes*

## 'Developing' Transplantation in Japan

As the dispute over brain death remains open, PCPS challenges an even more conservative and long-accepted definition of death as cardio-circulatory arrest. Death is redefined (once more), this time through the relationship between different body systems, in a way that almost seems to run against the very logic that underpins the concept of death as brain death (the equation of human death with the death of one single organ). Kitanaka-sensei's story thus reminds us of how the answers to the above questions are both based on and inform distinctions –between life and death, persons and body parts, good and bad– that are not only socially constructed, but also constantly changing. The situation of organ transplantation in Japan has significantly transformed since the years of the 'brain death problem'. New problems have emerged, while the definition of death still remains contested terrain. Through the above discussion, I have attempted to map some of these transformations, and the human experiences though which they materialised.

For transplant patients, advocates, and professionals, the sense of this change translated into the optimistic hope that donation will increase in the future, and in the appreciation of slowly gained but solid achievements.

> You can't say where we'll be in fifty years, but you know where we were ten years ago. I think that, somewhere, [donations] will increase, hopefully. If you look forward you can't see the path, but if you look back you do. I don't know how things will be in five years, but since five years ago, or ten years ago, there has been a change.
>
> (JOTNW coordinator, Umeyara)

The reform of the law on brain death and transplants in 2009, twelve years after the passing of what Ashida-san called 'the traffic light without the road', arguably represented the most visible instantiation of such change. The reform was the outcome of lengthy political negotiations, of the renewed media interest and public debate over the problem of transplant, as well as of the international pressure deriving from the growing awareness of the phenomenon of transplant tourism and trafficking (Chapter 5). The experience of Japanese transplant patients emerged throughout the discussion as the key domain underscoring these transformations, starting from the example of *ZōiRen*'s lobbying activity.

In the midst of the notorious 'brain death problem', Japanese patients suffering from a wide range of diseases for which transplant came to represent the hope of a cure gave raise to new forms of social organisations –patients' groups- aimed at fostering mutual help and peer-exchange. These have become the sites where new forms of politically charged activism emerged, which addressed the policy making process as a means to prompt social change. Patients and their families have organised to negotiate their claims in the public arena harnessing strategic resources. Through the plight of *tokō ishoku* families, they reached the medias' ears to mobilise emotional response in the public, while lobbying MPs "one by one" to influence political decisions (Chapter 5).

The study of the *ZōiRen*'s campaign has revealed a not very well-known case of socio-political activism on contemporary health-related matters. While patients' contestation of brain death in Japan has been widely discussed (Feldman 2000; Lock 2002), the study of transplant advocacy, and of how it

interweaved with the long-enduring controversy on the 'brain death problem', calls attention to various aspects of the national debate on transplantation, and sheds some light of the dynamics through which these have emerged as 'social problems' in Japan. The analysis of how transplant recipients and their families came to play a prominent role as key political and social actors in the debate and regulation of this medical technology contributes valuable insights to the growing literature on patients' organisations and health-related movements (Epstein 1995; Hoffman 2011; Novas 2006; Rose 2007; Landzelius 2006; cf. Petryna 2002; Biehl 2004). This, it seems, has overwhelmingly focused on the North American and European contexts, maybe unsurprisingly given the assumption that Japan is a harmonious and hierarchical society. Filling this gap, the thesis adds to the case studies of patients' mobilisation and grass-roots movement in Japan (George 2001; Kingston 2004; cf. Hirano 2008), to highlight in particular the role of patients as policy actors.

The validation of the worth of transplantation, however, is by no means confined to the 'promotion of transplantation' in the public arena, for the question of efficacy remains a question that *ishokusha* and their families are personally confronted with as they navigate their post-operative life juggling therapeutic expectations and the responsibilities of after-care. As ethnographies of transplant patients' experience in other contexts show, becoming an organ recipient entails the constant negotiation of 'normality' (Crowley-Matoka 2005; Sharp 1999, 2006). In this respect, the ethnography of Japanese recipients shows that forms of social organisation on a health-related basis were also the privileged sites where people negotiate what it means to be '*ishokusha*' (transplanted person) in the country of the 'brain death problem'. This social panorama of care, I argue, greatly complicates the common interpretation that recipients are co-opted in the promotion of transplantation out of a sense of gratitude towards those who helped them, often at the costs of censoring their problems and complains so as to not contradict the positive rhetoric of transplant promotion (Sharp 2006; Gordon 1996). It is not my intention to negate that socially agreed expectations, of health and gratitude, shape people's therapeutic experience of recipients and their families; at the same

time, however, the ethnography of Japanese patients repositions them as active agents who make good use of their indebtedness.

The first patients groups, emerging in the 1990s, were formed to provide mutual support and practical guidance to recipients and candidates at a time when not only organ donation was contested on ethical grounds, but the therapeutic efficacy of transplantation too was disputed and the treatment was not commonly on offer in Japan (Chapter 5). While transplantation can be said to be better established within the Japanese health-care system and more approvingly represented in the public discourse than in the past, transplant recipients are still not very numerous and becoming an '*ishokusha'* means, in their own terms, to belong to a 'minority group', albeit one that people like Nakamichi-san have worked hard to define in a positive light.

The summer camp for young recipients, the transplant games, and the friendships born and cultivated in the waiting room are, therefore, the sites where patients can confront each other on the small and larger issues of life after the operation with people who share the same experience, and especially for the *tokō ishoku* (who are in a way a 'minority within a minority') these are often the only resource of support in the absence of hospital-based groups, or social worker or transplant coordinators' assistance. Through these forms of sociality, therefore, people negotiate their 'return to a normal life' (*shakai fukki*) against normative, and almost hegemonic, assumptions of 'normality' as health and productiveness. Tomomatsu argues that for Japanese recipients (especially of an older generation) overcoming social stigma for their condition is a crucial part of the post-operative life (2013). The ethnography reflects in part this point, but it also indicates that there is more at stake in the dynamics through which patients 'author and authorise' (Landzelius 2006: 543) what it means to be '*ishokusha'* in Japan.

Within the Japanese landscape, where the promotion of transplant in the public arena and the mutual support among patients are but two sides of one coin, one of the things that, I believe, is strongly reasserted about being an organ recipient is that it is acceptable to *receive*. If one of the arguments against the redefinition of death for transplantation purposes was that it removes death from the circle of close ones in order to use the person's body to

help strangers (Lock 2002), the ethnography shows that underpinning the transformation of transplantation in Japan is precisely the renegotiation of the networks of social and moral obligations in which death is entangled.

As I have shown, the legacy of the Japanese impasse on transplants has been the emergence of the phenomenon of transplants overseas. Through *tokō ishoku*, people rely on various resources within and without the health-care system, including fellow recipients, patients' rights advocacy, health care professionals, the media and the public, in order to pursue overseas the treatment they cannot receive at home (Chapters 2 and 4). In asserting these uninsured claims to care, Japanese recipients strategically negotiate relationships of indebtedness: they validate their worth as recipients of aid by sharing their plight with the public; they construe advocacy as a means to return the favour received (*ongaeshi*); they denounce the transplants overseas as a burden (*meiwaku*) that Japan imposes on others in order to lobby for the reform of national policies. It is through the negotiation of these circuits of reciprocity that transplant patients have legitimised and asserted the right to receive, both abroad and especially at home.

The social embeddedness of Japanese practices of exchange has often been given as a reason behind the local uneasiness with transplantation. While the 'gift of life' is an anonymous donation to strangers, gift giving in Japan, it has been pointed out, entails mutual reciprocity and is in fact used to reinforce and consolidate codified networks of social relationships (Tomomatsu 2013; Sasaki 2008; Lock 2002). Throughout my analysis, I have shown, however, that people negotiate reciprocity across different registers adapting the technology to the situations on the ground, and thus give rise to new and complex circuits of exchange. In this respect, while the recent discussion on organ transplantation within anthropology and the social sciences has argued for the need to move beyond the paradigmatic frameworks of analysis, centred on the theory of the gift, in order to articulate more nuanced descriptions of the actual economies in which body parts are caught up (Waldby and Mitchell 2006; Yamazaki 2009, 2011a, 2011b), this thesis offers a valuable and rare ethnographic contribution to a debate that has so far remained largely theoretical.

The discussion on the management of brain death in clinical practice illuminates one crucial site where these economies of organs are negotiated (Chapter 6). The analysis of the clinical care of brain death is, to my knowledge, the first attempt to investigate empirically physicians' attitudes towards the diagnosis of the condition and the 'option giving' after the enforcement of the new policy on organ donation, and shows that in fact nothing has changed compared to the past (cf. Aita 2012). Japan still hold its 'ambiguous' definition of brain death, both on paper and in practice, and this, as I have illustrated, offers an important space for care. While end-of-life is increasingly a matter of concern, and in light of the new policy on organ donation the practice of 'giving an option' has assumed a greater than ever importance to promote efficiency in organ donation, clinical practice emerges as the crucial site where people are more directly confronted with the question of how to reconcile the need to procure life-saving organs with the problem of making sense of the death of the person. I have illustrated in this regard how the moral obligations of care and the networks of social relationships that make the body into a person inform the medical categories at stake. Further, I have shown that transformations are always ongoing, so that the dilemma of how to define death continues to shape the local economies of organ transplants in ever shifting ways.

In mapping these economies, this thesis offers fresh insights into how people engage with organ transplantation in a country famous for its opposition to brain death. In doing so, it provides relevant ethnographic knowledge to the existing literature on this technology in anthropology and closely related disciplines[84], and contributes significantly to a subject so far poorly studied in the social sciences (cf. Tomomatsu 2013; Yamazaki 2007, 2009, 2011a, 2011b). Deviating from Tomomatsu's analysis (2013), which is closely focused on patients and their families' personal illness experience, I have tied my discussion of what it means to be '*ishokusha*' in Japan into the broader global and local economies of organs and revealed how they shape each other in significant ways. In doing so, I have weaved Yamazaki's theoretical insights on

[84] Among others: Fox and Swazey (1978); Sharp (2006); Ben-David (2005); Gordon (2001, 2006); Maynard (2006); Joralemon (1995); Crowley-Matoka (2005); Healy (2006), Strathern (2004); Ikels (2012); Shimazono (2008); Scheper-Hughes (2000, 2001, 2005); Cohen (2001, 2003, 2005).

'bioeconomies' (2009, 2011a, 2011b) into the ethnographic description of how these economies are negotiated on the ground through a variety of practices, such as the fundraising, patients' advocacy, and the problem of brain death at the juncture between public policy and clinical practice. From such a perspective, the thesis contributes to the still narrow body of literature on biotechnologies in Japan, showing how such an investigation can offer precious insights into the seemingly self-explanatory logic of 'global' technologies.

## Unfitting Parts

There is a second image that emerges from Kitanaka-sensei's account of advanced CPR, and is about the power of biotechnologies of disassembling the person into body spare parts. With PCPS the "heart can return to its normal function", but the device is ultimately aimed at "rescuing the brain." The problem is, that the two do not always die in the same way, hence the dilemma of how to adjust the use of the device to a medical practice that is aimed at "rescuing the person" and not just at "rescuing the organs." The vignette about PCPS shows that while we might live and die as hearts, brains and kidneys, the problem is how to reconfigure the ways in which we live and die as whole persons.

I chose the vignette about PCPS to wrap up my conclusions because it raises some of the key questions that run through the ethnography. To what extent is it desirable to technologically trickling with death, and where is the limit of attempting new ways to help those for whom "there is no next step"? Where does one stop in pursuing "miracles" if terrible deaths are likely to come with them? When does a clinical failure become tragic, and when does it leave "no regrets"? How to make sense of the uncertainty (*kamoshirenai*) that accompany these dilemmas? And who to whom are these decisions right or wrong, when close family members, unrelated patients and society s a whole partake in the individual's death? At the same time, the vignette about PCPS also indicates that these problems are not separate from one another but are negotiated against each other. The description of PCPS shows how its therapeutic capacity

depends on both the ability of operating on organs as separate parts as well as the calibration of these interventions in view of the interaction of different body systems. Borrowing on this image, one can rethink the technology as a means manage individual death in relation to collective life.

Arguably, it is when people are confronted directly with clinical decisions about life and death that these dilemmas emerge in the most striking and visible way. For families of young recipients, their children's illness faced them not only with the unexpected diagnosis of a life-threatening condition but also with the question of how to pursue care in a regime of scarcity where the only option of treatment is not on offer. In a society where children are highly valued and the burden of death is mostly carried by the elderly, the young age of the children and the rareness and severity of the disease define these episodes of illness as particularly critical cases. The extraordinariness of this mortality, in turn elicits the extraordinariness of the cure that transplant offers, as a resource-intensive and clinically uncertain treatment that pushes everyone, physicians, families, and patients, to leave nothing unattempted in the emotionally charged and momentous effort of 'saving lives' (chapter 2).

On the opposite hand, brain death faces people with forms of life that cannot be saved and that force medicine to reconfigure its goals: from avoiding death at any costs, to taking care of it (chapter 6). As the discussion on *mitori no iryō* shows, if the medicalisation of death is a problem, and one of great social relevance, it is medicine that is charged of reconfiguring a good death (cf. Kaufman). From this perspective, whether in the form of end-of-life care for the donor, or in the heroic enterprise of saving the lives of potential recipients, the high-end technology of transplantation is technique to handle situations where people are confronted with mortality in the form of unexpected and tragic life crises.

I have argued, however, that mortality also presents itself in much more ordinary ways. While the experience of receiving a transplant is often represented as momentous and exceptional one (and in many ways it undoubtedly is), its legacy continues long past the surgery (chapter 3). Even for the families of young patients who couldn't make it through, the life after the (attempted) transplant is characterised by the on-going process of reconciling

with those events. For healthy recipients, on the other hand, health itself becomes a matter of daily negotiation, as it's both highly cherished and always on the verge of becoming pathological. Knowing the hopes and investments people invest in the process of receiving a transplant, and how these shape the life after the operation, I am particularly cautious in overstretching comparisons between experiences that are sharply different. I have argued, however, that in their diversity, both the existential quandaries prompted by the loss of a child, and the negotiation of 'normality' that recipients are confronted with shed some light on one shared aspect of the technology: the way it works as a means to tame the precariousness and limitedness of life.

Bauman argues that the ever-present possibility and final certainty of death is productive of social life (1992). Similarly, Davis illustrates that the knowledge of death and the awareness of mortality signified by illness underpin the construction and reproduction of moral communities, as therapeutic practices becomes a means to mediate social life (2000, 2003). The ethnography shows that this is true not just for traditional therapeutic practices but for modern biotechnologies too. Contrary to the received argument that advanced medical technologies have stripped death away from the web of social relations in which it was construed, the discussion of how people in Japan have negotiated conflicting dilemmas regarding organ procurement and the redefinition of death shows how the technology is used as a means to collectively confront death. The circulation of therapeutic resources, moral sentiments and mutual favours through which people manage the procurement and allocation of organs for transplant are process of mor(t)al distribution through which the amount and forms of mortality that society can tolerate are collectively negotiated.

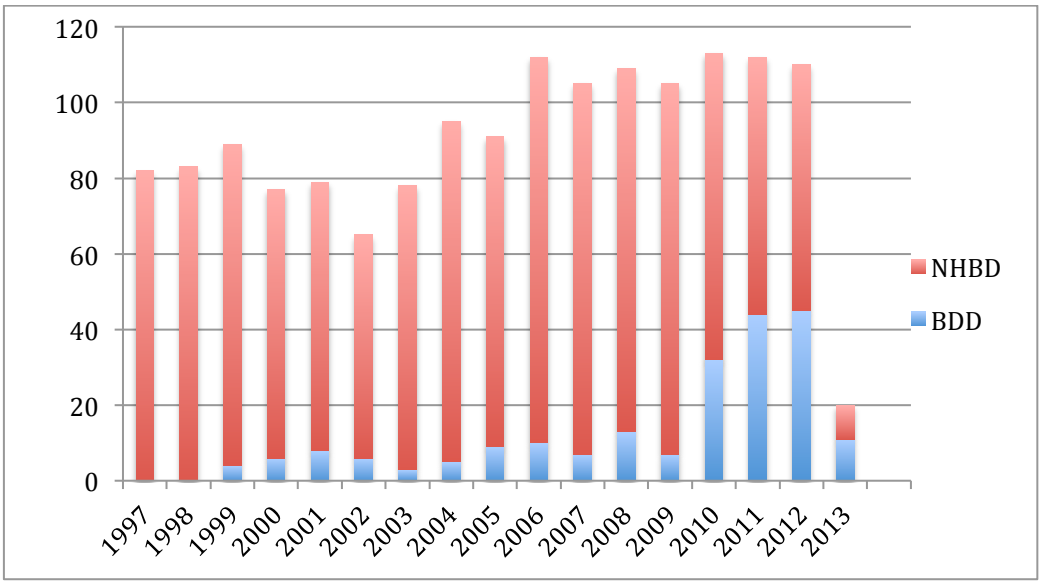
I have thus shown that through the fundraising campaigns, people identify critical forms of mortality and put in place the conditions to reconfigure a space where possible deaths become socially acceptable, albeit tragic: when no effort is left unattempted to save these lives, it will be something else (a shortage or organs, of time, or life itself) to take upon itself the burden of death. It was against these unacceptable deaths that transplant patients advocated for the need to Japan to carry its own burden as a country and avoid putting young

patients at risk. Compensating a potential waste of life thus became the means to redefine another shortage of life as good as death.

# APPENDIX 1

## Cadaveric Organ Donation in Japan

Including Brain Death Donation (BDD) and Non-Heart Beating Donation (NHBD)




Data from the Japan Organ Transplantation Network (1997-2013)

# APPENDIX 2

## Contents of the Bills of Reform

| | | | | |
|---|---|---|---|---|
| 2003 | Konō | Uniform Definition | Opt Out | None |
| 2005 | A | Uniform Definition<br>but<br>Right to Opt Out | Opt Out | None |
| 2005 | B | Limited to Organ Donation Only | Opt In | Lowered:<br>from 15 to 12 years old |
| 2007 | C | Limited to Organ Donation Only<br>&<br><br>Stricter Clinical Criteria | Opt In | Unchanged:<br>15 years old |
| 2009 | D | Limited to Organ Donation Only | Opt In | None |
| 2009 | A’ | Limited to Organ Donation Only | Opt Out | None |
| 2009 | E | No Change | No Change | Provisional Commission for the Study of Paediatric Brain Death |

# References


Abadie, Alberto and Sebastien Gay
2006. 'The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study.' *Journal of Health Economics* 25(4): 599–620.

Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain-Death
1968. 'A Definition of Irreversible Come.' *Journal of American Medical Association* 205 (6): 337-40.

Agamben, Giorgio
1998. *Homo Sacer : Sovereign Power and Bare Life*. Stanford: Stanford University Press
2009. "*What Is an Apparatus?" And Other Essays.* Stanford, Calif: Stanford University Press.

Aita, Karuoko
2012. '*Nōshi no 'Ri' to 'Jō': Zōki Ishoku to iu Iryō no naka de*' (Logics and Feelings of Brain Death in the Case of Transplantation). In: Kuramochi, Takeshi et al. (eds.) *Nōshi, Ishoku Iryō* (Brain Death and Transplantation). Tokyo: Maruzen.
2011. *Enmei Iryō to Rinshō Genba: Jinkō Kokyūki to Irō no Iryō Rinrigaku* (Life-Sustaining Treatment and Clinicians in Japan: Medical Ethics of Mechanical Ventilation and PEG Feeding). Tokyo: Tokyo University Press.
2009. 'Japan Approves Brain Death to Increase Donors: Will it Work?'. *The Lancet* 374(9699): 1403-1404.
2006. 'Withdrawal of Care in Japan. *Lancet* 368: 12-14.

Allison, Anne
1991. 'Japanese Mothers and *Obentōs*: The Lunch-Box as Ideological State Apparatus.' *Anthropological Quarterly* 64(4): 195.

Amos, Timothy D.
2011. *Embodying Difference: The Making of Burakumin in Modern Japan*. Honolulu: University of Hawai'i Press.

Appadurai, Arjun
1986. *The Social Life of Things: Commodities in Cultural Perspective.* Cambridge: Cambridge University Press.

Arnold, Robert M. and Stuart J. Youngner
1993. 'Back to Future: Obtaining Organs from Non-Heart-Beating Cadavers'. *Kennedy Institute of Ethics Journal* 3(2): 103:11.

Aruga, Akira
2006. '*Zōki Ishoku: Teikyō gawa ni okeru sho Mondai*' (Organ Transplants: Issues in Donor's Facilities) *Nichi Shō Shi* (Japan Journal of Gastroenterlogy) 108: 729-734.
2010. '*Nōshika ni okeru Zōki Ishoku wo Kangaeru*' (Organ Transplantations from the Brain Dead in Japan). *Nippon Rinshō* 68(12): 2161-2163.

*Asahi Shimbun*
2009a. *Nōshi ha Shi: Sanpi nibun* (Brain Death is Death: pros and cons). July, 23rd.
2009b. *Nōshi ha Hito no Shi: Nokoru Gimon* (Brain Death is Human Death: Remaining Doubts). July, 23rd.

Awa, Hiromi
2009. *Mirakuru bōi to yobareta* (They called him 'miracle boy'). Tokyo: Harusho

Bagheri, Alireza
2009. 'Japan Organ Transplantation Law: Past, Present and Future.' *Asian Bioethics Review* 1: 452–456.
2013. 'Global Initiatives to Tackle Organ Trafficking and Transplant Tourism.' *Medicine, Health Care, and Philosophy* 16(4): 887–895.

Bagheri, Alireza, and Francis L. Delmonico
2007. 'Individual Choice in the Definition of Death'. *Journal of Medical Ethics* 33(3): 146–149.

Bai, Kōichi (ed.)
1989. *Nōshi wo Manabu* (Learning Brain Death). Tokyo: Nihon Yōronsha

Bauman, Zygmunt
1992. *Mortality, Immortality and Other Life Strategies*. Oxford: Polity.

Befu, Harumi
1968. 'Gift-Giving in a Modernizing Japan.' *Monumenta Nipponica* 23(3/4): 445–456.
2001. *Hegemony of Homogeneity : An Anthropological Analysis of Nihonjinron*. Melbourne: Trans. Pacific Press.

Belkin, Gary S.
2014. *Death before Dying*. Oxford: Oxford University Press.

Ben-Ari, Eyal
1996. *Body Projects in Japanese Childcare: Culture, Organization and Emotions in a Preschool*. Richmond: Curzon.

1997. *Japanese Childcare: An Interpretive Study of Culture and Organization*. London: Kegan Paul International.

Ben-David, Orit Brower
2005. *Organ Donation and Transplantation: Body Organs as Exchangable Socio-Cultural Rescources*. Westport: Praeger.

Benedict, Ruth
2005 [1946]. *The Chrysanthemum and the Sword: Patterns of Japanese Culture*. Boston: Houghton Mifflin.

Benthal, Jonathan
2012. 'Charity.' In: Fassin, Didier, (ed.) 2012. *A Companion to Moral Anthropology*. Hoboken, New Jersey: Wiley-Blackwell.

Bernat, James L.
1998. 'A Defense of the Whole-Brain Concept of Death.' *The Hastings Center Report* 28(2): 14–23.

Berque, Augustin
1997. *Japan: Nature, Artifice, and Japanese Culture.* Northants. : Pilkington Press

Bestor, Theodor C.
2003. 'Inquisitive Observation: Following Networks in Urban Fieldwork.' In: Bestor, Theodore C., Patricia G. Steinhoff, and Victoria Lyon Bestor (eds.) *Doing Fieldwork in Japan*. Honolulu: University of Hawai'i Press.

Biehl, João, and Adriana Petryna
2011. 'Bodies of Rights and Therapeutic Markets'. *Social Research: An International Quarterly* 78(2): 359–386.

Blumstein, James F. and Frank A. Sloan
1989. *Organ Transplantation Policy : Issues and Prospects*. Durham: Duke University Press.

Bonhomme, Julien
2012. 'The Dangers of Anonymity: Witchcraft, Rumor, and Modernity in Africa'. *HAU: Journal of Ethnographic Theory* 2(2): 205–233.

Bornstein, Erica
2012. *Disquieting Gifts : Humanitarianism in New Delhi*. Stanford, California: Stanford University Press.

Campbell, John C.
1998. *The Art of Balance in Health Policy : Maitaining Japan's Low-Cost, Egalitarian System*. Cambridge: Cambridge University Press

Canguilhem, Georges

1991. *The Normal and the Pathological*. New York: Zone Books.

Clark, Rodney
1979. *The Japanese Company*. New Haven: Yale University Press.

Cohen, Lawrence
2001. 'The Other Kidney: Biopolitics beyond Recognition.' In: Scheper-Hughes, Nancy and Loïc Wacquant, *Commodifying Bodies*. London: Sage.
2003. 'Where It Hurts: Indian Material for an Ethics of Organ Transplantation'. *Zygon* 38(3).
2005. 'Operability, Bioavailability, and Exception.' In: Ong, Aihwa and Stephen J. Collier (eds.) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Oxford: Blacwell.

Condry, Ian
2011. 'Post-3/11 Japan and the Radical Recontextualization of Value: Music, Social Media, and End-Around Strategies for Cultural Action.' *International Journal of Japanese Sociology* 20(1): 4–17.

Connell, John
2011. *Medical Tourism*. Wallingford, Oxfordshire: CABI.

Cook, Emma E.
2009. *Failing Freeters : Young Men, Masculinity and Adulthood in Japan* Unpublished PhD Thesis.

Crapanzano, Vincent
2003. 'Reflections on Hope as a Category of Social and Psychological Analysis'. *Cultural Anthropology* 18(1): 3–32.

Crowley-Matoka, Megan
2005. 'Desperately Seeking "Normal": The Promise and Perils of Living with Kidney Transplantation'. *Social Science & Medicine* 61(4).

Csordas, Thomas J.
1990. 'Embodiment as a Paradigm for Anthropology'. *Ethos* 18(1): 5–47.

Das, Veena
1999. 'Public Good, Ethics, and Everyday Life: Beyond the Boundaries of Bioethics.' *Daedalus* 128(4): 99-133.

Daniels, Inge
2009. The Social Death of Unused Gifts: Surplus and Value in Contemporary Japan. *The Journal of Material Culture* 14(3): 385-408

Davis, Dena S.
2010. *Genetic Dilemmas : Reproductive Technology, Parental Choices, and Children's Futures*. Oxford: Oxford University Press.

Davis, Christopher
2000. *Death in Abeyance : Illness and Therapy among the Tabwa of Central Africa.* Edinburgh: Edinburgh University Press,.
2012. 'What Is Life Worth? A Rough Guide to Valuation'. *Medical Anthropology Quarterly* 26(4): 503–517.

Delvecchio Good, M. J., B. J. Good, C. Schaffer, and S. E. Lind
1990. 'American Oncology and the Discourse on Hope.' *Culture, Medicine and Psychiatry* 14(1): 59–79.

Doi, Takeo
1973. *The Anatomy of Dependence*. Tokyo: Kodansha International.

Duffield, Mark
2008. 'Global Civil War: the Non-Insured, Intellectual Containment and Post-Interventionist Society.' *Journal of Refugees Studies* 21(2): 145-165.

Einarsdóttir, Jónína
2004. *Tired of Weeping : Mother Love, Child Death, and Poverty in Guinea-Bissau*. Madison: University of Wisconsin Press.

Embree, John F.
1939. *A Japanese Village : Suye Mura*. London: University of Chicago Press

Epstein, Steven G.
1995. *Impure Science : AIDS, Activism, and the Politics of Knowledge.* London: Universtiy of California Press.

Fassin, Didier
2005. 'Compassion and Repression: The Moral Economy of Immigration Policies in France'. *Cultural Anthropology* 20(3): 362–387.
2007. 'Humanitarianism as a Politics of Life'. *Public Culture* 19(3): 499–520.
2013. 'Children as Victims: the Moral Economy of Childhood in the Times of AIDS'. In: Biehl, João G., and Adriana Petryna (eds.) *When People Come First : Critical Studies in Global Health*. Princeton, New Jersey: Princeton University Press.

Feldman, Eric A.
1985. 'Medical ethics the Japanese way.' *Hastings Cent Rep* 15, 21–24.
1994. 'Legal Transplants, Organ Transplants: The Japanese Experience'. *Social & Legal Studies* 3(1): 71–91.
2000. *The Ritual of Rights in Japan : Law, Society and Health Policy*. Cambridge: Cambridge University Press.

Fisker-Nielsen, Anne-Mette
2012. *Religion and Politics in Contemporary Japan: Soka Gakkai Youth and Komeito.* New York: Routledge.

Fox, Renée C.
1993. '"An Ignoble Form of Cannibalism": Reflections on the Pittsburgh Protocol for Procuring Organs from Non-Heart-Beating Cadavers.' *Kennedy Institute of Ethics* 3(2): 231-39.

Fox, Renée C., Judith P. Swazey and Judith C. Watkins
1978. *The Courage to Fail : A Social View of Organ Transplants and Dialysis*. London: University of Chicago Press.
1992. *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press.
2008. *Observing Bioethics*. Oxford: Oxford University Press.

Franklin, Sarah
1997. *Embodied Progress : A Cultural Account of Assisted Conception*. London: Routledge.

Frühstück, Sabine
2003. *Colonizing Sex : Sexology and Social Control in Modern Japan*. Berkeley, CA: University of California Press.

Fujita, Misao, Brian Taylor Slingsby and Akira Akabayashi
2010. 'Transplant Tourism From Japan'. *The American Journal of Bioethics* 10(2): 24–26.

Geertz, Clifford
1974. '"From the Native's Point of View": On the Nature of Anthropological Understanding.' *Bulletin of the American Academy of Arts and Sciences* 28(1): 26.

George, Timothy S.
2001. *Minamata : Pollution and the Struggle for Democracy in Postwar Japan*. Cambridge, Mass.: Harvard University Press.

Gervais, Karen Grandstrand
1986. *Redefining Death*. New Haven: Yale University Press.

Gluck, Carol
1985. *Japan's Modern Myths : Ideology in the Late Meiji Period*. Princeton, N.J.: Princeton University Press.

Goodman, Roger
2000. *Children of the Japanese State : The Changing Role of Child Protection Institutions in Contemporary Japan*. Oxford: Oxford University Press.
2002a. (ed.) *Global Japan : The Experience of Japan's New Immigrants and Overseas Communities*. London: RoutledgeCurzon.
2002b. (ed.) *Family and Social Policy in Japan : Anthropological Approaches*. Cambridge: Cambridge University Press.

Gordon, Elisa J.
2000. ‘Preventing Waste: A Ritual Analysis of Candidate Selection for Kidney Transplantation’. *Anthropology & Medicine* 7(3): 351–372.
2001. “They Don’t Have to Suffer for Me”: Why Dialysis Patients Refuse Offers of Living Donor Kidneys’. *Medical Anthropology Quarterly* 15(2). New Series: 245–267.

Gordon, Elisa J, Thomas R. Prohska and Ashwini R. Seghal
2008. ‘The Financial Impact of Immunosuppressant Expenses on New Kidney Recipients.’ *Clinical Transplantation*. 22: 738-48.

Gupta, Akhil and James Ferguson
1992. ‘Beyond “Culture”: Space, Identity, and the Politics of Difference’. *Cultural Anthropology* 7(1): 6–23.
1997. *Anthropological Locations: Boundaries and Grounds of a Field Science*. London: University of California Press.

Hakim, Nadey S. and Vassilios E. Papalois (eds.)
2003. *History of Organ and Cell Transplantation*. London: Imperial College Press.

Halevy, Amir and Baruch Brody
1993. ‘Brain Death: Reconciling Definitions, Criteria, and Tests.’ *Annals of Internal Medicine* 119(6): 519–525.

Hall, John W.
1970. *Japan from Prehistory to Modern Times.* New York: Delacorte Press.

Hamdy, Sherine
2012. *Our Bodies Belong to God : Organ Transplants, Islam, and the Struggle for Human Dignity in Egypt*. London: University of California Press.

Hamilton, David
2012. *A History of Organ Transplantation*. Pittsburgh: University of Pittsburgh Press.

Hart, Keith, Jean-Louis Laville, and Antonio David Cattani
2010. *The Human Economy : A Citizen’s Guide*. Cambridge ; Malden, MA: Polity.

Healy, Kieran J.
2006. *Last Best Gifts : Altruism and the Market for Human Blood and Organs*. Chicago: University of Chicago Press.

Hearn, Lafcadio
1901. *Glimpses of Unfamiliar Japan*. New York: Houghton, Mifflin.

Hendry, Joy
1986. *Becoming Japanese: The World of the Pre-School Child*. Honolulu: University of Hawaii Press.
1987. *Understanding Japanese Society*. London: Croom Helm.

Hirano, Mari
2008. *The AIDS Epidemic among Haemophiliacs in Japan : The Mothers' Narratives*. Unpublished PhD Thesis.

Hirsch, Eric and Marilyn Strathern (eds.)
2006. *Transactions and Creations: Property Debates and the Stimulus of Melanesia.* New York: Berghahn Books.

Hoffman, Beatrix, Nancy Tomes, Rachel Grob and Mark Schlesinger (eds.)
2011. *Patients as Policy Actors : A Century of Changing Markets and Missions*. Piscataway: Rutgers University Press.

Hogle, Linda F.
1995. 'Standardization across Non-Standard Domains: The Case of Organ Procurement.' *Science, Technology, & Human Values* 20(4): 482–500.
1999. *Recovering the Nation's Body: Cultural Memory, Medicine, and the Politics of Redemption*. New Brunswick, N.J: Rutgers University Press.

Horiguchi, Sachiko
2011. 'Hikikomori: How Private Isolation Caught the Public Eye.'In: Goodman, Roger, Imoto, Yuki, and Toivonen Tuukka (eds.) *A Sociology of Japanese Youth: From Returnees to NEETs.* New York: Routledge.

Hoshino, Kazumasa
1997. *Japanese and Western Bioethics: Studies in Moral Diversity*. Boston: Kluwer Academic Publishers.

Ida, Makoto
2011. '*Kaisei Zōki Ishoku Hō ni Kansuru Shi no Gainen* (The Concept of Death in the Reformed Act on Organ Transplants).' In: Machino, Saku, Terayuki Yamamoto, and Satoko Tetsui (eds.) *Ishoku Iryō no Korekara* (The Future of the Transplantation Medicine). Tokyo: Shinzansha.

Igarashi, Yoshikuni
2000. *Bodies of Memory: Narratives of War in Postwar Japanese Culture, 1945-1970*. Princeton, N.J.: Princeton University Press.

Ikegami, Naoki, Byung-Kwang Yoo, Hideki Hashimoto et al.
2011. 'Japanese Universal Health Coverage: Evolution, Achievements, and Challenges'. *The Lancet* 378(9796): 1106–1115.

Ikels, Charlotte

2012. ‘The Evolution of Bioethics in China: the Case of Organ Transplantation’.*Harvard Asia Q*. 14(4): 57-65.
2013. ‘The Anthropology of Organ Transplantation’. *Annual Review of Anthropology* 42(1): 89–102.

Ivry, Tsipy
2010. *Embodying Culture : Pregnancy in Japan and Israel.* New Brunswick, N.J.: Rutgers University Press.

Janzen, John M.
1987. ‘Therapy Management: Concept, Reality, Process’. *Medical Anthropology Quarterly* 1(1). New Series: 68–84.

Jasanoff, Sheila
1997. *Science at the Bar : Law, Science, and Technology in American Law*. London: Harvard University Press

Joralemon, Donald
1995. ‘Organ Wars: The Battle for Body Parts’. *Medical Anthropology Quarterly* 9(3): 335–356.
2001. ‘Shifting Ethics: Debating the Incentive Question in Organ Transplantation.’ *Journal of Medical Ethics* 27(1): 30–35.

Joralemon, Donald and Phil Cox
2003. ‘Body Values: The Case against Compensating for Transplant Organs.’ *Hastings Center Report* 33(1): 27–33.

JTRO (Japan Transplant Recipients’ Organisation) (ed.)
1994. *Ishokusha Toshite Tsutaetai Koto* (Things I Want to Tell as a Transplant Recipient). Tokyo: Harusho Pub.

Kakumu, Yūko
2009. *Mama arigatō* (Thank you Mum). Tokyo: Kadokawa.

Kangas, Beth
2007. ‘Hope from Abroad in the International Medical Travel of Yemeni Patients’. *Anthropology & Medicine* 14(3): 293–305.

Kano, Hitoshi
2008. ‘*Zōki Soshiki Teikyō no Ishi wo Ukasu tame ni*’ (Making Use of The Will to Donate Organs and Tissues). *Kyō no Ishoku* (Transplantation Now) 21 (1): 33-43.
2011. *Zōki Teikyō ni okeru Mitori no Iryō no Jūyōsei* (The Importance of ‘Mitori Care’ in Organ Donation. *Igaku no Ayumi* 237 (5): 453-456.

Kato, Masae, and Margaret Sleeboom-Faulkner
2011a. ‘Meanings of the Embryo in Japan: Narratives of IVF Experience and Embryo Ownership.’ *Sociology of Health & Illness* 33(3): 434–447.

2011b. ‘Dichotomies of Collectivism and Individualism in Bioethics: Selective Abortion Debates and Issues of Self-Determination in Japan and “the West.”’ *Social Science & Medicine* 73(4): 507–514.

Kaufman, Sharon R.
2000. ‘In the Shadow of “Death with Dignity”: Medicine and Cultural Quandaries of the Vegetative State.’ *American Anthropologist* 102(1). New Series: 69–83.
2006. *…And a Time to Die : How American Hospitals Shape the End of Life*. Chicago: University of Chicago Press.

Kaufman, Sharon R. and Lynn M. Morgan
2005. ‘The Anthropology of the Beginnings and Ends of Life’. *Annual Review of Anthropology* 34: 317–341.

Kelly, William W.
1991. ‘Directions in the Anthropology of Contemporary Japan.’ *Annual Review of Anthropology* 20(1): 395–431.

King, Nancy M. P.
2006. ‘Fame and Fortune: the “Simple” Ethics of Organ Transplantation’. In: Wailoo, Keith, Julie Livingston, and Peter Joseph Guarnaccia, (eds.) *A Death Retold: Jesica Santillan, the Bungled Transplant,and Paradoxes of Medical Citizenship*. Chapel Hill: University of North Carolina Press.

Kingston, Jeff
2004. *Japan’s Quiet Transformation: Social Change and Civil Society in the Twenty-First Century*. London: Routledge Curzon.

Kitanaka, Junko
2012. *Depression in Japan : Psychiatric Cures for a Society in Distress*. Princeton: Princeton University Press.

Kitzinger Celia, and Jenny Kitzinger
2014. ‘“This In-Between”’: How Families Talk About Death in Relation to Severe Brain Injury and Disorders of Consiousness’. In: Van Brussel, Leen and Nico Carpentier (eds.) *The Social Construction of Death: Interdisciplinary Perspectives*. Basingstone: Pelgrave.

Kleinman, Arthur
1988. *The Illness Narratives: Suffering, Healing, and the Human Condition.* New York: Basic Books.
1999. ‘Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for the New “Bioethics”.’ *Daedalus*128(4): 69-97.

Kinsella, Sharon
2014. *Schoolgirls, Money and Rebellion in Japan*. London: Routledge.

Koch, Tom
2001. *Scarce Goods : Justice, Fairness, and Organ Transplantation*. Santa Barbara: ABC-CLIO.

Koenig, Barbara A. and Linda F. Hogle
1995. 'Organ Transplantation (Re)Examined?' *Medical Anthropology Quarterly* 9(3): 393–397.

Kondo, Dorinne K.
1990. *Crafting Selves : Power, Gender, and Discourses of Identity in a Japanese Workplace.* Chicago: University of Chicago Press.

Krauss, Ellis S., Thomas P. Rohlen and Patricia G. Steinhoff (eds.)
1984. *Conflict in Japan*. Honolulu: University of Hawaii Press.

Kuramochi, Takeshi
2012. Gōhōsei to Rinrisei (Lawfulness and ethics). In: Kuramochi, Takeshi et. al. (eds.) *Nōshi, Ishoku Iryō (Brain Death and Transplantation).* Tokyo: Maruzen.

Latour, Bruno
1988. *The Pasteurization of France*. Cambridge: Harvard University Press
1993. *We Have Never Been Modern*. London :: Harvester Wheatsheaf
2007. (2005). *Reassembling the Social : An Introduction to Actor-Network-Theory*. Oxford: Oxford University Press.

Lebra, Takie S.
1976. *Japanese Patterns of Behavior.* Honolulu: University of Hawaii Press.

Leder, Drew
1990. *The Absent Body*. London: University of Chicago Press.

Lederer, Susan E.
2008. *Flesh and Blood: Organ Transplantation and Blood Transfusion in Twentieth-Century America. O*xford: Oxford University Press.

Livingston, Julie
2012. *Improvising Medicine : An African Oncology Ward in an Emerging Cancer Epidemic*. Durham: Duke University Press.

Lock, Margaret
1993. *Encounters with Aging : Mythologies of Menopause in Japan and North America*. London: University of California Press.
1996. 'Death in Technological Time: Locating the End of Meaningful Life.' *Medical Anthropology Quarterly* 10(4): 675-600.

1997. ‘The Unnutural as Ideology: Contesting Brain-Death in Japan.’ In Asquith and Kalland (eds.) *Japanese Images of Nature: Cultural Perspectives*. Richmond: Curzon Press.
2001. ‘Eliminating Stigmatization: Application of the New Genetics in Japan.’ In: Makhlouf Obermeyer, C. (ed.) *Cultural Perspectives on Reproductive Health*. Oxford: Oxford University Press.
2002. *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkley: California University Press.

Long, Susan O.
1999. ‘Shikata ga nai: Resignation, Control, and Self-Identity in Japan. In: Long, Susan Orpett (ed.) *Lives in Motion: Composing Circles of Self and Community*. Ithaca, N.Y.: East Asia Program: Cornell University.
2001. ‘Negotiating the “Good Death”: Japanese Ambivalence about New Ways to Die.’ *Ethnology* 40(4): 271–289.
2003. ‘Becoming a Cucumber: Culture, Nature, and the Good Death in Japan and the United States..’ *Journal of Japanese Studies* 29(1): 33–68.
2005. *Final Days : Japanese Culture and Choice at the End of Life*. Honolulu: University of Hawaii Press.

Low, Morris (ed.)
2005. *Building a Modern Japan: Science, Technology, and Medicine in the Meiji Era and beyond.* New York: Palgrave Macmillan.

Lynn, Joanne and Ronald Cranford
1999. ‘The Persisting Perplexities in the Determination of Death.’ In: Youngner, Stuart J., Robert M. Arnold, and Renie Schapiro, (eds.). *The Definition of Death: Contemporary Controversies*. Baltimore: Johns Hopkins University Press.

Machino, Saku, Terayuki Yamamoto and Satoko Tetsui (eds.)
2009. *Ishoku Iryō no Korekara* (The Future of the Transplantation Medicine). Tokyo: Shinzansha.

Marshall, Patricia A.
1992. ‘Anthropology and Bioethics’. Medical Anthropology Quarterly 6(1). New Series: 49–73.

Martin, Emily
1984. ‘Pregnancy, Labor and Body Image in the United States’. *Social Science & Medicine* 19(11): 1201–1206.
1990. ‘Toward an Anthropology of Immunology: The Body as Nation State’. *Medical Anthropology Quarterly* 4(4). New Series: 410–426.
1992. ‘The End of the Body?’. *American Ethnologist* 19(1): 121–140.
1994. *Flexible Bodies : Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS.* Boston: Beacon Press.

Martinez, Dolores P.
2007. (ed.) *Modern Japanese Culture and Society.* London: Routledge.

2005. ‘On the “Nature” of Japanese Culture, or, Is There a Japanese Sense of Nature?’ In: Robertson, Jessica (ed.) *A Companion to the Anthropology of Japan*. Oxford: Blackwell.
2014. (ed.) *Gender and Japanese Society*. Abingdon: Routledge.

Mathews, Gordon
2004. ‘On the Tensions Between Japanese and American Anthropological Depictions of Japan.’ In: Yamashita, Shinji, Joseph Bosco, and Jeremy S. Eades (eds.) *The Making of Anthropology in East and Southeast Asia*. New York: Berghahn Books.

Matsuno, Ryoichi
1998. ‘Aja ni okeru Nihonjin ni yoru “Jin Ishoku Tsua” no Jittai (Investigative Research on the State of Japanese Kidney Transplant Tourism in Asia)’, *Seimei Rinri* (Japan Association for Bioethics) 8 (1): 69-74.

Mauss, Marcel
1970. *The Gift : Forms and Functions of Exchange in Archaic Societies*. London: Cohen & West.

Maynard, Ronald J.
2006. ‘Controlling Death: Compromising Life: Chronic Disease, Prognostication, and the New Biotechnologies’. *Medical Anthropology Quarterly* 20(2): 212–234.

McLein, Iain, Jo Poulton
1986. Good Blood, Bad Blood and the Market: *The Gift Relationship* Revisited. *Journal of Public Policy* 6(4): 431-445

McVeigh, Brian J.
1998. *The Nature of the Japanese State : Rationality and Rituality*. London: Routledge.

Miller, Laura
2006. *Beauty up : Exploring Contemporary Japanese Body Aesthetics*. London: University of California Press.

Miyazaki, Hirokazu
2000. ‘Faith and Its Fulfillment: Agency, Exchange, and the Fijian Aesthetics of Completion’. *American Ethnologist* 27(1): 31–51.

Mol, Annemarie
2002. *The Body Multiple: Ontology in Medical Practice*. London: Duke University Press.
2008. *The logic of care : health and the problem of patient choice*. Routledge, Abingdon, Oxon ; New York.

Mollaret, Pierre. and Maurice Goulon

1959. ‘The depassed coma (preliminary memoir)’. *Revue Neurologique* 101: 3–15.

Moniruzzaman, Monir
2012. ‘“Living Cadavers” in Bangladesh: Bioviolence in the Human Organ Bazaar.’ *Medical Anthropology Quarterly* 26(1): 69–91.

Morioka, Masahiro
1989. *Nōshi no Hito: Seimeigaku no Shiten kara* (Brain Death People: a Bioethical Perspective). Tokyo: Tokyo Shoseki.
2001. ‘Reconsidering Brain Death: A Lesson from Japan’s Fifteen Years of Experience’. *Hastings Center Report* 31(4): 41.

Murphy, Robert F.
2001. *The Body Silent*. New York: Norton.

Murray, Last
1981. ‘The importance of knowing about not knowing.’ *Social Science & Medicine* 15: 387–392.

Nakajima, Michi
1985. *Mienai shi: Nōshi to Zōki Ishoku* (The Invisible Death: Brain Death and Organ Transplants). Tokyo: Bungei Shunju.

Nakamura, Karen
2006. *Deaf in Japan: Signing and the Politics of Identit*. Ithaca, N.Y.: Cornell University Press.
2014.’Barrier-Free Brothels: Sex Volunteers, Prostitutes and People with Disabilities.’In: Roberts, Glenda, Kawano, Satsuki, and Susan Long (eds.) *Capturing Contemporary Japan: Differentiation and Uncertainty.* Honolulu: University of Hawaii Press.

Nakane, Chie
1970. *Japanese Society.* London: Weidenfeld & Nicolson.

Nakayama, Tarō
2011. *Kokuminteki gōi wo mezashita iryō: zōki ishokuhō no seiritsu to kaisei made no 25nen (*Medicine in search of popular consensus: on the 25 years leading to the creation and reform of the law on transplants*).* Tokyo: Harusho.

Namihira, Emiko
1988. *Nōshi, Zōki Ishoku, Gan Kokuchi: Shi to Iryō no Jinruigaku* (Brain Death and the Disclosure of Cancer Diagnoses: an anthropology of Medicine and Death). Tokyo: Fukutake Shoten.

Naraindas, Harish and Cristiana Bastos
2011. ‘Healing Holidays? Itinerant Patients, Therapeutic Locales and the Quest for Health’. *Anthropology & Medicine* 18(1): 1–6.

*New York Times*
1987. *A transplant Trauma: Is Soul-Searching Ending?* February, 10th.
2009a. *Report of 'Organ Tourism' Stirs New Japan-China Controversy.* November, 7th.
2009b. *In Surgery, a Tangled Tumour Meets its Match*. December 14.
2011. *For illegal immigrant, line is drawn at transplant*, December 20.

Nguyen, Vinh-Kim
2005. 'Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship'. In: Ong, Aihwa and Stephen J. Collier (eds.) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Oxford: Blacwell.

Nie, Jing-Bao
2010. *Japan's Wartime Medical Atrocities: Comparative Inquiries in Science, History, and Ethics*. New York: Routledge.

Noël, Luc and Dominique Martin
2009. 'Progress Towards National Self-Sufficiency in Organ Transplants.' *Bulletin of the World Health Organization* 87(9):647.

Norbeck, Edward and Margaret M. Lock
1987. *Health, Illness, and Medical Care in Japan : Cultural and Social Dimensions.* Honolulu: University of Hawaii Press.

Norgren, Tiana
2001. *Abortion before Birth Control : The Politics of Reproduction in Postwar Japan*. Princeton, N.J.: Princeton University Press.

*Nōshi Rinchō* (*Rinji Nōshi oyobi Zōki Ishoku Chōsakai*)
1992. *Nōshi Oyobi Zōki Ishoku ni kansuru Jūyō Jiko ni tsuite* (Final Resport by the Provisional Commission for the Study of Brain Death and Transplants). Tokyo: Ministry of Health Labour and Welfare.

Novas, Carlos
2006. 'The Political Economy of Hope: Patients' Organizations, Science and Biovalue'. *BioSocieties* 1(03): 289–305.

Nudeshima, Jirō
1991. 'Obstacles to Brain Death and Organ Transplantation in Japan'. *The Lancet* 338(8774): 1063.

Ohnuki-Tierney, Emiko
1984. *Illness and Culture in Contemporary Japan : An Anthropological View*. Cambridge: Cambridge University Press.
1994. 'Brain Death and Organ Transplantation: Cultural Bases of Medical Technology'. *Current Anthropology* 35(3): 233–254.

Ong, Aihwa and Stephen J. Collier
2005. *Global Assemblages : Technology, Politics, and Ethics as Anthropological Problems*. Oxford: Blackwell Pub.

Ormond, Meghan
2011. 'Medical Tourism, Medical Exile: responding to the Cross-Border Pursuit of Healthcare in Malaysia.' In Minca, Claudio and Timothy Oakes (eds.) *Real Tourism: Practice, Care and Politics in Contemporary Travel*. London: Routledge.
2012. 'Harnessing "diasporic" medical mobilities.' In: Thomas, Felicity, and Jasmine Gideon (eds.) *Migration, Health and Inequality*. Zed Books, London.
2014a. (Forthcoming). 'Medical tourism.' In: Lew, Alan A., C. Michael Hall and Allan Williams *The Wiley- Blackwell Companion to Tourism,* edited by. Malden, MA: John Wiley & Sons.
2014b. (Forthcoming). 'What's where? Why there? And why care? A geography of responsibility in medical tourism'. In: Lunt, J. Hanefeld, and D. Horsfall (eds.). *Handbook on Medical Tourism and Patient Mobility*. London: Edward Elgar.

Orsini, Michael and Miriam Smith
2010. 'Social Movements, Knowledge and Public Policy: The Case of Autism Activism in Canada and the US'. *Critical Policy Studies* 4(1): 38–57.

Osteen, Mark
2002. *The Question of the Gift: Essays Across Disciplines*. London: Rotledge
Pallis, Christopher
1996. *ABC of Brainstem Death*. London: BMJ Publishing Group.

Parry, Jonathan
1986. The Gift, the Indian Gift and the 'Indian Gift'. *Man* 21(3): 453-473.

Parry, Jonathan and Maurice Bloch (eds.)
1989. *Money and the Morality of Exchange*. Cambridge: Cambridge University Press.

Pekkanen, Robert
2006. *Japan's Dual Civil Society: Members Without Advocates.* Stanford University Press.

Petryna, Adriana
2002. *Life Exposed: Biological Citizens after Chernobyl*. Oxford: Princeton University Press.

Pharr, Susan J. and Ellis S. Krauss, (eds.)
1996. *Media and Politics in Japan*. Honolulu: University of Hawai'i Press

Plath, David W.
1980. *Long Engagements, Maturity in Modern Japan*. Stanford, Calif: Stanford University Press.

Porter, Roy (ed.)
2006. *The Cambridge History of Medicine*. Cambridge: Cambridge University Press.

Pottage, Alain
1998. 'The Inscription of Life in Law: Genes, Patents, and Bio-Politics'. *The Modern Law Review* 61(5): 740–765.

Price, David H.
2008. *Anthropological Intelligence : The Deployment and Neglect of American Anthropology in the Second World War*. Durham: Duke University Press.

Rabinow, Paul
2005. 'Artificiality and Enlightenment: From Sociobiology to Biosociality.' In: Xavier Indra Jonathan (ed.) *Anthropologies of Modernity: Foucault, Governmentality, and Life Politics*. Oxford: Blackwell.

Radcliffe-Richards, J., A. S. Daar, R. D. Guttmann et al.
1998. 'The Case for Allowing Kidney Sales.' *The Lancet* 351(9120): 1950–1952.

Radin, Patricia
2006. '"To Me, It's My Life": Medical Communication, Trust, and Activism in Cyberspace.' *Social Science & Medicine* (1982) 62(3): 591–601.

Rapp, Rayna
2000. *Testing Women, Testing the Fetus : The Social Impact of Amniocentesis in America*. Hoboken: Taylor and Francis.

Raveri, Massimo
1984. *Itinerari nel Sacro: l'Esperienza Religiosa Giapponese* (Sacred Journeys: the Japanese Religious Experience). Venezia: Ca' Foscarina.
1992. *Il Corpo e il Paradiso: Esperienze Ascetiche in Asia Orientale* (The Body and Heaven: the Ascetic Experience in Asia). Venezia: Marsilio.

Reader, Ian
2000. *Religious Violence in Contemporary Japan : The Case of Aum Shinrikyō*. Honolulu: University of Hawaii Press.

Redfield, Peter
2012. 'Bioexpectations: Life Technologies as Humanitarian Goods'. *Public Culture* 24(1 66): 157–184.

Reich, Michael R., Naoki Ikegami, Kenji Shibuya and Keizo Takemi
2011. '50 Years of Pursuing a Healthy Society in Japan.' *The Lancet* 378(9796): 1051–1053.

Reubi, David
2011. 'The Promise of Human Rights for Global Health: A Programmed Deception?'. *Social Science & Medicine* 73(5): 625–628.

Reynolds, David K.
1980. *The Quiet Therapies : Japanese Pathways to Personal Growth*. Honolulu: University Press of Hawaii.

Reynolds Whyte, Susan, Michael A. Whyte, Lotte Meirnet, and Jennifer Twebaze
2013. 'Therapeutic Clientiship: Belonging in Uganda's Projectified Landscape of AIDS Care. In: Biehl, João G., and Adriana Petryna (eds.) *When People Come First : Critical Studies in Global Health*. Princeton, New Jersey: Princeton University Press.

Riles, Annelise
2001. *The Network inside out*. Ann Arbor, Mich.: University of Michigan Press.

Roberts, Glenda S.
1994. *Staying on the Line : Blue-Collar Women in Contemporary Japan.* Honolulu: University of Hawaii Press.

Robertson, Jennifer
1998. 'When and Where Japan Enters: American Anthropology Since 1945' In: Hardcare, Helen (ed.) *The Postwar Development of Japanese Studies in the United States*. Boston: Brill.
2002. 'Blood Talks: Eugenic Modernity and the Creation of New Japanese'. *History and Anthropology* 13(3): 191–216.
2008. *A Companion to the Anthropology of Japan*. Oxford: Blackwell.

Rose, Nikolas S.
2007. *The Politics of Life Itself : Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Oxford: Princeton University Press.

Rothman, David J.
2003. *Strangers at the Bedside : A History of How Law and Bioethics Transformed Medical Decision Making*. New York: Aldine de Gruyter.

Rupp, Katherine
2003. *Gift-Giving in Japan : Cash, Connections, Cosmologies.* Stanford: Stanford University Press.

Ryang, Sonia

2004. *Japan and National Anthropology: A Critique.* London: Routledge.

Sasaki, Kaori
2008. 'Popularizing Organ Transplantation in Japan: Travelling Iceboxes as the "Relay of Life"'. *Science As Culture* 17(3): 293–316.

Sato, Akira
2003. '*Nōshi Hantei ni okeru Hojōteki Shindan no Ishigi*' (Ancillary Examinations in Cofirmation of Brain Death). *Geka Chiryō* 89(3): 341-342.

*Saturday Evening Post*
1968. '*Frankeistein in South Africa*'. February, 10th.

Scheper-Hughes, Nancy
1992. *Death without Weeping: The Violence of Everyday Life in Brazil*. Oxford: University of California Press.
2000. 'The global traffic in human organs.' *Current Anthropology* 41(2): 191-224.
2001. 'Commodity Fetishism in Organs Trafficking'. *Body & Society* 7(2-3): 31–62.
2005. 'The Last Commodity: Post-Human Ethics and the Global Traffic in "Fresh" Organs.' In: Ong, Aihwa and Stephen J. Collier (eds.) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Oxford: Blacwell.

Scheper-Hughes, Nancy and Margaret M. Lock
1987. 'The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology.' *Medical Anthropology Quarterly* 1(1). New Series: 6–41.

Schlich, Thomas
2010. *The Origins of Organ Transplantation: Surgery and Laboratory Science, 1880-1930*. Rochester, NY: University of Rochester Press.

Schwartz, Frank J.
1991. *Advice and Consent : The Politics of Consultation in Japan*. Cambridge, Mass.: Harvard University.

Sharp, Lesley A.
1995. 'Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self'. *Medical Anthropology Quarterly* 9(3). New Series: 357–389.
1999. 'A Medical Anthropologist's View on Posttransplant Compliance: The Underground Economy of Medical Survival'. *Transplantation Proceedings* 31(4, Supplement 1): 31S–33S.
2006. *Strange Harvest : Organ Transplants, Denatured Bodies, and the Transformed Self*. London: University of California Press.

Shimazono, Yosuke
2007. 'The State of the International Organ Trade: A Provisional Picture Based on Integration of Available Information.' *Bulletin of the world Health Organization.*
2008. Repaying and Cherishing the Gift of Life: Gift Excahnge and Living-Related Kindey Transplantation in the Philippines. *Anthropology Action* 5(3): 34-46.

Shewmon, Alan D.
1998a. '"Brainstem Death," "Brain Death" and Death: A Critical Re-Evaluation of the Purported Equivalence.' *Issues in Law & Medicine* 14(2): 125–145.
1998. '"Brainstem Death," "Brain Death" and Death: A Critical Re-Evaluation of the Purported Equivalence.' *Issues in Law & Medicine* 14(2): 125–145.
2001. 'The Brain and Somatic Integration: Insights Into the Standard BiologicalRationale for Equating "Brain Death" With Death.' *Journal of Medicine & Philosophy* 26(5): 457.

Siminoff, Laura A. and Kata Chillag
1999. 'The Fallacy of the "Gift of Life."' *The Hastings Center Report* 29(6): 34–41.

Simmel, Georg, Tom Bottomore and David Frisby
1978. *The Philosophy of Money*. London: Routledge and Kegan Paul.

Skloot, Rebecca
2011. *The Immortal Life of Henrietta Lacks*. New York: Broadway Books.

Slater, David H.
2013. 'Moralities of Voluntary Aid: the Permutations of Gifts and their Reciptocals.' In: Gill, Tom, Brigitte Steger, and David H. Slater, (eds.) *Japan Copes with Calamity: Ethnographies of the Earthquake, Tsunami and Nuclear Disasters of March 2011*. New York: Peter Lang.

Smith, Bardwell L.
2013. *Narratives of Sorrow and Dignity: Japanese Women, Pregnancy Loss, and Modern Rituals of Grieving*. Oxford: Oxford University Press.

Smith, Robert J.
1974. *Ancestor Worship in Contemporary Japan*. Stanford, Calif.: Stanford University Press.
1999. 'The Living and the Dead in Japanese Popular Religion'. In: Long, Susan Orpett (ed.) *Lives in Motion: Composing Circles of Self and Community*. Ithaca, N.Y.: East Asia Program: Cornell University.

Solomon, Harris
2011. 'Affective Journeys: The Emotional Structuring of Medical Tourism in India.' *Anthropology & Medicine* 18(1): 105–118.

Spielvogel, Laura
2003. *Working out in Japan : Shaping the Female Body in Tokyo Fitness Clubs*. Durham: Duke University Press.

Stacey, Jamese T.
2005. *Stakes and Kidenys: Why Markets in Human Body Parts Are Morally Imperatuve.* Aldershot: Ashgate

Stahelin, Hartmann F.
1996. 'A History of Cyclosporine A (Sandimmune) revisited: another point of view.' *Experientia* 52.

Steffánson, Halldór
1995. 'On Structural Duality in Japanese Conceptions of Death: Collective Forms of Death Rituals in Morimachi.' In: van Bremen, Jan, and Dolores P. Martinez (eds.) *Ceremony and Rituals in Japan: Religious Practices in an Industrialised Society*. London: Routledge.

Steinhoff, Patricia G.
2003. 'New Notes from the Underground: Doing Fieldowork Without a Site.' In: Bestor, Theodore C., Patricia G. Steinhoff, and Victoria Lyon Bestor (eds.) *Doing Fieldwork in Japan*. Honolulu: University of Hawai'i Press.

Strathern, Marilyn
1992. *After Nature : English Kinship in the Late Twentieth Century*. Cambridge: Cambridge University Press.
1998. 'Divisions of Interest and Langugaes of Ownership.' In: Hann, Chris M. *Property Relations Renewing the Anthropological Tradition* Cambridge: Cambridge University Press.
2004. 'Losing (Out On) Intellectual Resources.' In: Pottage, Alain and Martha Mundy (eds.) *Law, Anthropology, and the Constitution of the Social: Making Persons and Things.* Cambridge: Cambridge University Press.

Sugimoto, Yoshio
2003. *An Introduction to Japanese Society.* Cambridge: Cambridge University Press.

Suzuki, Hikaru
2000. *The Price of Death : The Funeral Industry in Contemporary Japan*. Stanford: Stanford University Press.
2003. (ed.) 'The Japanese Way of Death.' In: Bryant, Clifton D. (ed.) *Handbook of Death & Dying*. Thousands Oaks, CA: Sage Pub.
2013 (ed.) *Death and Dying in Contemporary Japan*. New York: Routledge.

Suzuki, Iwayumi

2012. ‘Beyond Ancestor Worship: Continued Relationship with Significant Others.’ In: Suzuki, Hikaru (ed.) *Death and Dying in Contemporary Japan*. New York: Routledge.

Suzuki, Taku
2010. *Embodying Belonging : Racializing Okinawan Diaspora in Bolivia and Japan*. Honolulu: University of Hawai‘i Press.

Tachibana, Takashi
1986. *Nōshi*: *Brain Death, Cerebral Death, Brain Stem Death*. Tōkyō: Chūō Kōronsha.

Taussig, Michael
1977. ‘The Genesis of Capitalism Amongst a South American Peasantry: Devil’s Labor and the Baptism of Money.’ *Comparative Studies in Society and History* 19(2): 130-155.

Teubner, Gunther
1989. ‘How the Law Thinks: Toward a Constructivist Epistemology of Law.’ *Law & Society Review* 23(5): 727.

Titmuss, Richard M.
1970. *The Gift Relationship : From Human Blood to Social Policy*. New York: Vintage Books.

Tomomatsu, Ikuko
2011. *Heart transplantation: its risks, the expectations, and cultural negotiations in Japan*. Unpublished PhD Thesis.

Traphagan, John W.
2000. *Taming Oblivion : Aging Bodies and the Fear of Senility in Japan*. New York : State University of New York Press.

TRIO Japan (ed.)
2009. *Kyō no inochi wo sukuu tame ni: ishoku iryō to watashi, ishoku shien katsudō kara* (Saving this life: my story with transplantation, and the struggles to promote it). Tokyo: Harusho.

Trohler, Ulrich
1993. ‘Surgery (Modern).’ In: Porter, Roy, and William F. Bynum (eds.) *Companion Encyclopedia of the History of Medicine*. London: Routledge.

Truog, Robert D.
1997. ‘Is It Time to Abandon Brain Death?’ *The Hastings Center Report* 27(1): 29–37.

Tsuji, Yohko

2011 ‘Death Policies in Japan: the State, the Family and the Individual.’ In: Goodman, Roger (ed.) *Family and Social Policy in Japan : Anthropological Approaches*. Cambridge: Cambridge University Press.

Uryūhara, Yōko
2012. *Iryō no Soshiki Inobeeshon: Purofesshonarizumu ga Ishoku iryō wo Ugokasu* (Innovations and the Medical System: Why Professionalism Can Drive Transplantation). Tokyo: Chūō Keizai Sha.

Veatch, Robert M.
1977. ‘Death and Dying: The Legislative Options.’ *The Hastings Center Report* 7: 5–8.
1989. *Death, Dying and the Biological Revolution: Our Last Quest for Responsibility*. London: Yale University Press.

Vogel, Ezra F.
1979. *Japan as Number One : Lessons for America*. London: Harvard University Press.

Wailoo, Keith, Julie Livingston and Peter Joseph Guarnaccia (eds.)
2006. *A Death Retold: Jesica Santillan, the Bungled Transplant,and Paradoxes of Medical Citizenship*. Chapel Hill: University of North Carolina Press.

Williams, N.
1996. *The right to life in Japan* London: Routledge.

Waldby, Cathy and Robert Mitchell
2006. *Tissue Economies : Blood, Organs, and Cell Lines in Late Capitalism*. Durham: Duke University Press.

Wijdicks, Eelco F. M.
2011. *Brain Death*. New York: Oxford University Press.
2012. ‘The Transatlantic Divide over Brain Death Determination and the Debate.’ *Brain: A Journal of Neurology* 135(4): 1321–1331.

Whittaker, Andrea, Lenore Manderson and Elizabeth Cartwright
2010. ‘Patients without Borders: Understanding Medical Travel.’ *Medical Anthropology* 29(4): 336–343.

Yamaguchi Ken’ichirō
2011. *Nōshi, ishoku iryō Q&A50: donaa no tachiba de ‘inochi’ wo kangaeru* (Fifty questions on brain death and transplants: thinking ‘life’ from the donor’s perspective). Tokyo: Kaimeisha.

Yamashita, Shinji, Joseph Bosco and Jeremy S. Eades (eds.)
2004. *The Making of Anthropology in East and Southeast Asia*. New York: Berghahn Books.

Yamazaki, Gorō
2007. *Gurobaruka no naka ishokuiryō:kaigai tokō ishokusha no sentaku* (Globalised transplantation: the choice to travel overseas). In Ukigaya, Sachiyo. and Takashi Iguchi (eds.) *Yamai to 'tsunagari' no ba no minzokishi*. Tokyo: Akashi ed.
2009. *Karada wo Teikyō Suru/Uru: Zōki Ishoku no Keizai* (Donating/Selling the Body: the Economies of Organ Transplants). In: Oda, Tatsuya and Juntarō Fukada (eds.) *Keyzai kara Dasshu: Shirizu*.
2011a. *Zōki Ishoku no Sei-Keizai: Chiryō kara Kazu Chōsei he* (The Bioeconomies of Organ Transplants: from Treatment to Computation). In: Higaki Tatsuya ed. Sei-Kenryokuron no Genzai: Foucault kara *Gendai wo Yomu* (Contemporary Bio-Politics: from Faoucalt to the 21st Century). Tokyo: Keishō.
2011b. *Zōki Ishoku ni Arawareru Shintai and Jinkaku: Sei-Keizai ni okeru Zōyoron no tame ni* (Persons and Bodies in Organ Donation: Rethinking Gifts in the Age of Bioeconomy). *Bunka Jinrui Gaku (*Cultural Anthropology) 76 (3): 308-328.
2013. 'From Cure to Governance: The Biopolitical Scene after the Brain Death Controversy in Japan.' *East Asian Science, Technology and Society*. 7(2): 243-279.

*Yomiuri, Shinbun*
1968a. *Nihon shō no shinzō Ishoku* (First Japanese Heart Transplant). August, 8th.
1968b. *Dosanko no Hankotsu to Shinzō: 'Nihon Igakkai Semai' Karute* (Resistance and Heart of the Hokkaiō-born doctor: 'Japanese Medicine is a Small World). August, 12th.
1968c. *Beddo Hanare Isu de Chōshoku* (Leaving the Bed and Sitting for Breakfast). August, 19th.
2009a. *Zōki Ishoku, Naze Kaisei Kiun: 'Tokō Kishoku' WHO ga Raigetsu Shishin* (Good Time for a Reform: WHO 'Self-Restriction of the Transplants Overseas' Expected to Be Issued Next Month). April, 22nd.
2009b. *Neage no Honne: Nihonjin Haijo* (The Truth Behind the Price Raise: Excluding the Japanese). June, 18th.
2009c. '*Nōshi ha Hito no Shi' Zōki Ishokuhō Kaisei: Yōji no Hantei Kijun Kentō he* (Approved the Reform of Brain Death as Human Death: towards a Standard for the Determination in Children). July, 14 th.

Yoneyama, Shoko
1999. *The Japanese High School: Silence and Resistance*. London: Routledge.

Young, Allan
1982. 'The Anthropologies of Illness and Sickness.' *Annual Review of Anthropology* 11: 257-85.

Youngner, S. J., C. S. Landefeld, C. J. Coulton, B. W. Juknialis and M. Leary

1989. '"Brain Death" and Organ Retrieval. A Cross-Sectional Survey of Knowledge and Concepts among Health Professionals.' *JAMA* 261(15): 2205–2210.

Youngner, Stuart J., Robert M. Arnold and Renie Schapiro (eds.)
1999. *The Definition of Death: Contemporary Controversies*. Baltimore: Johns Hopkins University Press.

## Audio Visual Materials

*BBC*
1968. Tomorrow's World Special. 'Barnard faces his critics'.

*Fuji TV*
2011 Non Fix. *'Sono Toki Kazoku ha…Inochi no Genba de Kudasu Handan Totsuzen no Wakare to Zōki Ishoku* (When Families are Faced with Decisions about Life: Sudden Departures and Organ Transplants).

*Sapporō TV*
2010. HTB *Non Fikushon. 'Inochi to Shi no Iryō'* (Medicine for Life and Death).

*Fuji TV*
2008. *'Dōshite Susumanai ka: Nihon no Zōki Ishoku'* (Organ Transplantation in Japan: why it never developed).

## On-line sources

Istanbul Delcaration on Organ Trafficking Transplant Tourism
http://www.hks.harvard.edu/cchrp/isht/study_group/2010/pdf/DeclarationOfInstanbul.pdf

JOTNW
http://www.jotnw.or.jp/

Kimura-sensei wikipaedia page
http://en.wikipedia.org/wiki/Tomoaki_Kato

Komeno-san's testimony
http://www.shugiin.go.jp/internet/itdb_kaigiroku.nsf/html/kaigiroku/018716920080603001.htm (*first accessed on January, 20, 2014*)

Nuffield Council on Bioethics (2011) ‘Human Bodies: Donation for Medicine and Research’
http://nuffieldbioethics.org/project/donation/

*ZōiRen* Webpage
http://www.isyoku.net/profile.html

WHO (World Health Organisation)
Global glossary of terms and definition on donation and transplantation:
http://www.who.int/transplantation/activities/GlobalGlossaryonDonationTransplantation.pdf
Guiging Principles of Human Cell, Tissue and Organ Donation:
http://www.transplant-observatory.org/SiteCollectionDocuments/wholegethgp.pdf